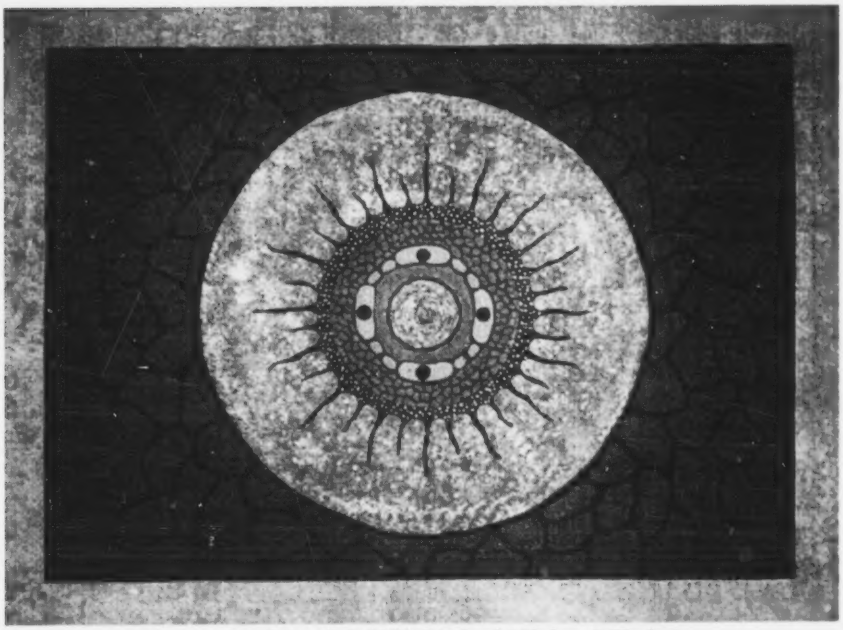
"It's Our Responsibility…"

Report of the Aboriginal Cancer Care Needs Assessment



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Aboriginal Cancer Care Unit

Cancer Care Ontario

November 2002

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The Four Medicines – The circle represents life, no beginning and no ending. We keep moving and growing. The four people within the circle represent the four sacred medicines used in ceremonies: Tobacco, Sweetgrass, Sage and Cedar. The medicines are used for prayers and cleansings. The fire in the centre is the Sacred Fire. The fire is kept burning for the duration of the sacred ceremony.

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As said by the words of the Elder …. "go to the people and they will give you the answers". We have gone to the people and their words will guide us.

Chi-Meegwetch,

Carmen R. Jones
Manager
Aboriginal Cancer Care Unit

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First Nation Communities

- Alderville First Nation
- Brunswick House First Nation
- Chippewas of Georgina Island
- Delaware First Nation
- Eabametoong First Nation
- Kingfisher Lake First Nation
- Mohawks of Akwesasne
- Moose Cree First Nation
- North Caribou Lake First Nation
- Ojibways of Batchewana
- Oneida Nation of the Thames
- Shoal Lake #40 First Nation
- Six Nations of the Grand River
- Temagami First Nation

Aboriginal Communities

- Fort Frances
- Iron Bridge
- Ottawa
- Sudbury
- Thunder Bay
- Toronto
- Windsor

PREFACE

In September 1996, Cancer Care Ontario met with the Aboriginal organizations across Ontario to form the Joint (Cancer Care) Ontario-Aboriginal Cancer Committee. The Committee developed and released a report in March 1997 entitled, ***New Beginnings: Planning Cancer Care for Aboriginal Peoples***. This report serves as the "structure and strategy" product of the partnership between Cancer Care Ontario and the Aboriginal organizations. The report recognized that the conventional western methods of delivering health care services do not reach the Aboriginal population.

In 2001, the Aboriginal Cancer Care Unit (ACCU) of Cancer Care Ontario (CCO) committed to conducting a province wide analysis of cancer issues in the Aboriginal population. This needs assessment was funded by Cancer Care Ontario, the Ministry of Health and Long Term Care, including funds from the Ontario Tobacco Strategy. The purpose of the needs assessment was to explore the Aboriginal Cancer Strategy. As much as possible, all people involved in conducting this study were of Aboriginal origin, and the process followed was compatible with the culture of the Aboriginal people.

This initiative was challenging, because it was the first time a provincial cancer agency has undertaken a study of this magnitude. Conducting a community-based assessment with the largest provincial Aboriginal population in Canada encompassing remote geographic areas, urban centres and diverse cultures was an incredibly complex undertaking. In addition to involving grassroots Aboriginal people, cancer service providers were also consulted for their point of view. The scope of the needs assessment was limited by time and financial considerations, any community-based study of this scale, involves travel to isolated communities. Nevertheless, care was taken to ensure that diverse Aboriginal community perspectives were incorporated in the design and conduct of the study, including the analysis and interpretation of the findings.

This needs assessment is not academic research, but rather was participatory in nature, focusing on identifying those cancer issues important to Ontario's Aboriginal community. The study was predominantly, yet not exclusively, qualitative in nature. It gives a holistic picture of Aboriginal cancer needs across Ontario; it was not conducted to provide region-specific data.

This document will serve as a tool to plan, develop and implement strategies to address cancer needs of Aboriginal people in Ontario. The report is organized to present the findings according to the objectives that were originally identified in the planning process.

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1.0 INTRODUCTION

1.1 The Aboriginal Cancer Care Unit (ACCU)

In 1996, the Ontario Cancer Treatment and Research Foundation (OCTRF), now Cancer Care Ontario (CCO), acknowledged that Aboriginal people did not have adequate access to health care services. Recognizing the need to work in collaboration with the Aboriginal community in addressing their health needs, they invited representatives from the Aboriginal organizations in Ontario to participate on the Joint (Cancer Care) Ontario - Aboriginal Cancer Committee (JOACC).

Members of the JOACC consist of: one Elder, and representatives from the Ontario Métis Aboriginal Association, the Métis Nations of Ontario, Anishnabek Nation – Union of Ontario Indians, the Association of Iroquois and Allied Indians, Nishnawbe Aski Nation, Grand Council Treaty #3, Independent First Nations, the Ontario Federation of Indian Friendship Centres, the Ontario Native Women's Association, and Cancer Care Ontario.

The JOACC began meeting in September of 1996. In March 1997, they released a document entitled, *New Beginnings: Planning Cancer Care for Aboriginal Peoples*. This report serves as the "structure and strategy" product of that partnership. It outlines the guiding principles and recommendations to support future cancer care initiatives developed to reach, educate and support the Aboriginal community.

The holistic perspective (physical, mental, emotional and spiritual) of healing and wellness and the concept that individual, family and community are inseparable, are paramount to the Aboriginal cancer care strategies which have evolved through this initiative. *New Beginnings* describes how community-generated involvement will be achieved through an integration of varying forms and levels of support, leadership and action. Plans include approaches to cultural sensitivity, communication, research and funding.

New Beginnings was accepted and supported by the Ontario Chiefs' Special Assembly in 1997. In 2000, based on recommendation from the report, an Aboriginal Cancer Care Unit (ACCU) was established, and its manager position was filled in March 2000.

The ACCU vision emphasizes collaborative partnerships with Aboriginal communities to ensure that Aboriginal people have timely, equitable access to an integrated system of excellent, co-ordinated and efficient programs in prevention, early detection, care, education and research.

The ACCU aims to:

- build knowledge and an understanding between CCO and the Aboriginal community;
- promote and achieve effective communications;
- provide education and awareness on cancer related services; and
- train Aboriginal health professionals and community members on cancer and related services.

The guiding principles of the ACCU are:

1. To develop trust between Aboriginal communities and the heath care providers built on mutual respect, sharing and mutual responsibility;
2. To achieve the commitment of Aboriginal leaders to provide leadership that ensures that Aboriginal people, both on and off-reserve, are involved, informed and educated in cancer care services related to prevention and treatment;
3. To respect and incorporate holistic practices of Aboriginal people which encompass the emotional, spiritual, physical and mental aspects of well-being;
4. To ensure program delivery which incorporates, through community involvement, translation services and information in Aboriginal languages/dialects;
5. To focus special attention on developing education and prevention programs targeting Aboriginal youth; including education, prevention, early detection and treatment.
6. To deliver programs which stress that individuals take responsibility for and control of their own health.

1.2 Background

Many challenges that are unique to the Aboriginal population must be considered in analysing cancer-related issues. A fundamental question that must be discussed is, ***what makes these issues distinct for Aboriginal people?***

First, there is a myth that cancer is rare among Aboriginal people. This belief is widespread in Aboriginal health literature and was raised by health care professionals who participated in the needs assessment. This is simply not true. The cancer incidence rate among Aboriginal people is increasing; in fact cancer is the second most common cause of death in Aboriginal people. Belief in the myth that cancer is rare among Aboriginal people is dangerous. It could contribute to late diagnosis and misdiagnosis and creates an environment in which the possibility of cancer is not taken as seriously as it should be, by both Aboriginal people and health care professionals. The belief that Aboriginal people do not get cancer may partly come from the fact that the First Nations languages in Ontario do not have a word for cancer; many of the Aboriginal participants in the Needs Assessment felt that it is a new and foreign disease.

Second, culturally appropriate information about cancer is not readily available to the Aboriginal population. This is due to remoteness for the large northern population, limited access to Aboriginal health professionals who would be aware of cultural nuances in dealing with patients and lack of culturally sensitive material. Many different dialects and language groups make it difficult to translate existing information, and lack of Aboriginal language vocabulary to explain technical terms such as diagnosis, chemotherapy, and radiation compound the problem. Unless patients and families understand the concepts of screening, early detection, prevention, treatment and aftercare, they are not likely to comply with or trust the process of disease management. Having access to appropriate information enables people to make informed decisions about their health.

Third, First Nations people must cope with a complex and fragmented health care system that is under provincial, federal and First Nations jurisdictions. This system operates very differently than the mainstream health system does for non-First Nation residents of Ontario. For example, many drugs and procedures require prior approval by the federal government before they will be funded. The application process is complicated and lengthy for both patients and physicians. Frequently health care professionals do not understand the implications for the patient, and the result can be delay, reapplication, frustration, and potentially lack of approval and service. In addition, responsibility for patient care is divided between the levels of authority, and there is no case co-ordination system in place across the province. This likely results in regional disparity throughout the continuum of care.

Fourth, the age distribution of Aboriginal people differs from the rest of Ontario. According to Statistics Canada, the average age of the Aboriginal population in 1996 was 25.5 years, 10 years younger than the general population. Two-thirds (2/3) of the Aboriginal population is under 30 years of age. With such concentrations in the younger groups, the older age groups are relatively small. Only 4% of the Aboriginal population are aged 65 or over, compared with 12% of the general population. In the future, the number of new cancer cases can be expected to increase as the Aboriginal population ages. These demographics may have contributed to the myth (already noted) about lower cancer incidence among Aboriginal people.

Fifth, there is lack of research and cancer surveillance data specific to the Aboriginal population. The studies that have been done are often with small samples. Most are published in medical journals from the United States where culturally sensitive research and conferences on cancer in Native American are more prevalent. In Canada, information about Aboriginal cancer care needs comes primarily from research conducted in the North West Territories, British Columbia, and more recently, Ontario. In terms of cancer surveillance in Ontario, a comprehensive picture of current trends in Aboriginal cancer patterns would require considerable investment and co-ordination across federal and provincial jurisdictions and Aboriginal organizations. Clearly there is a need to expand, enhance and update the surveillance data in Ontario to adequately address cancer in the Aboriginal population.

Sixth, life circumstances over which the Aboriginal population has had no control have put them at higher risk for poor health. These include the reserve system that dictates where they can live, low housing standards, poor water quality, and lack of resources to correct socio-economic inequities. Imposed governance systems (the *Indian Act*), limited access to health care resources, high turnover of health care professionals, lack of continuity and co-ordination in care and treatment, language barriers, remoteness and isolation are circumstances that continue to exist. It is important to understand that Aboriginal people do not have the same lifestyle options and choices that are available to other residents of Ontario and for this population these risk factors are largely unavoidable and difficult to change. These risk factors need to be considered in planning and delivering cancer services to the Aboriginal population.

Finally, the cultural concepts of disease management are very different in the Aboriginal population. The holistic approach is the fundamental to Aboriginal cultures, so the western approach of site-specific disease management is not well accepted. For Aboriginal people the concept of wholeness and balance is fundamental and incorporates an essential belief that the physical, mental, spiritual and emotional aspects of life are connected and cannot be separated. This affects all aspects of cancer management and contributes to a general attitude of mistrust and pessimism toward available mainstream cancer services.

The cumulative effect of these circumstances has contributed to unique challenges that must be considered. In attempting to understand and analyse the full impact of cancer on the Aboriginal population, it is important to proceed with a perspective that carefully considers the whole picture, in keeping with a holistic approach. The Needs Assessment and this report are a first step, providing an opportunity to learn from Aboriginal people, their communities, and health care workers about their cancer care needs.

> "First Nations must be included in the decision making processes. The solutions cannot come from the outside. We must be at the table when health and social issues are being discussed."
>
> *The National Chief of the Assembly of First Nations, Matthew Coon Come, National Health Conference First Nation Health: Our Voice, Our Decisions, Our Responsibility, February 25, 2001*

1.3 Who are Ontario's Aboriginal People?

1.3.1 History of Aboriginal people in Ontario

It is estimated that First Nations people inhabited North America for at least 40,000 years prior to contact with Europeans. At the time of contact, there were approximately 500,000 Aboriginal people living here.[1]

Many Nations were nomadic and lived in semi-permanent dwellings, moving from one place to another following migration patterns and seasonal availability of food. Others lived in permanent villages and practised agriculture. Aboriginal people were unique and diverse, but shared a spiritual relationship and respect for the natural world. A holistic view was inherent in their way of life and they believed in the interrelationship between all living things on earth. Aboriginal people saw themselves as the caretakers of Mother Earth and held ceremonies and traditional feasts to honour spiritual guides, the earth and all its resources. Ceremonies were held following the hunt of sacred animals such as the bear, buffalo or the deer, and to thank the Creator for the gifts that Mother Earth provided.

Prior to contact with Europeans, the Aboriginal population of Ontario represented diverse and stable communities whose economy and governance were intact and thriving. Cultural identity was largely defined by linguistic affiliation, with Algonquin and Iroquois being the predominant languages. Aboriginal people lived in relatively good health with a balanced diet and lifestyle that ensured physical fitness. Disease was rare and highly respected healers had treatments for most of the ailments that occurred. First Nations had well-developed concepts of health and medicine prior to contact with Europeans, (Volume 3, Report of the Royal Commission on Aboriginal People). Good health meant more than the physical well being of an individual, it meant a balance of physical, spiritual, emotional and social health of individuals and communities.

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[1] This is a widely debated figure, 500,000 is the most widely accepted, some consider this a conservative estimate. *Royal Commission on Aboriginal People*, Volume 1, Chapter 2, Section 3.

Two historical events dramatically changed the healthy life balance enjoyed by Aboriginal people. First, communicable diseases were brought from Europe and caused depopulation. Disease such as smallpox, measles, typhoid fever and tuberculosis spread with devastating speed through a population with no resistance. It is estimated that the populace in some areas was reduced by 95%, (Thomas Berger, 1991). The enormous loss of life meant that entire segments of knowledge and skills were lost forever. Kinship structure and social functions were disrupted. The oral tradition of communities meant that much of the history and technical expertise vanished. When illness struck, people turned to community healers who were unable to cure the foreign diseases. Over time, the role of these wise and skilled practitioners was diminished, as people lost confidence in their abilities.

The second event to dramatically affect the Aboriginal population was European colonization, which began in the late 1700's. Settlers moved into territories previously controlled by various Aboriginal groups, which increased the competition for food and necessitated dramatic lifestyle changes for the Aboriginal population. Widespread invasive agriculture meant that huge areas of forest were destroyed. Prior to colonization, the fur trade and Aboriginal style of agriculture left the forest intact. Most of Ontario was covered in old growth forest, but trees were the enemy of the settlers whose first task was to clear the land. Aboriginal people were faced with great changes to their to traditional hunting and fishing grounds. Treaties were the governments' solution to restrict Aboriginal peoples control and use of the land, and their movement from place to place. The onset of colonization also meant an imposition of European religions, value systems, social structures, and orders of governance. The end result for Aboriginal communities were disruptions to traditional economic, governance and religious foundations of their society.

1.3.2 Ontario's Aboriginal people today

Statistics Canada defines the Aboriginal population as those who identify with one or more Aboriginal groups (North American Indian, Métis, or Inuit), including those who reported that they were registered/treaty Indians or band/First Nation members. According to Statistics Canada, the Aboriginal population of Ontario in 1996 was 141,520[2]. The Department of Indian Affairs and Northern Development (DIAND) defines the Aboriginal population count as those people who are identified as status Indian or Inuit according to the *Indian Act*. By that definition, the population of registered Indians in Ontario was 146,113 in 1998. Of these, 74,790 (51%) live on reserve and 71,323 (49%) live off reserve. There are also Métis people, who have a registered population of 12,000 in Ontario according to the Métis Registry of the Métis Nation of Ontario, (source: www.metisnation.org/insideMNO/registry.html). The Ontario Métis Aboriginal Association represents approximately 200,000 Aboriginal people in Ontario, including Métis, Status and non-status Indians living off-reserve, (source: www.omaa.org/aboutomaa.htm).

The pattern of age distribution among Aboriginal people is different from the general population – Ontario's Aboriginal population is youthful and growing. Almost 2/3 of the Aboriginal population is under 30. Children under 15 account for 35% of all Aboriginal people and youth aged 15 – 24 make up 18 % of the population. With such concentrations in younger ages, the older age groups are relatively small. Only 4% of the Aboriginal population is aged 65 or over.

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[2] The count of Aboriginal people in the 1996 census should be considered with caution. The enumeration was not complete, and 77 Indian reserves, many in Ontario, did not participate.

There are 137 First Nations in Ontario, located throughout the province, with more in the north than in the south. In the south, Aboriginal people live in large concentrations in urban centres and in Aboriginal communities. In the north, remoteness is a challenge for many First Nations communities. Approximately 50% of the First Nations (status Indian) population does not live on a reserve. Furthermore, Métis and non-status Aboriginal people do not live on reserve, so the number of Aboriginal people who live off reserve is much higher than those who live on First Nation reserves.

First Nations have historically been caught in jurisdictional disputes between federal and provincial governments over who has responsibility for their health and social welfare. The *Constitution Act, 1867* divides governing powers over various matters between the two levels of government. Section 91(24) of the *Act* vests the power over "Indians and lands reserved to Indians" to the federal government as its fiduciary responsibility. The federal government provides certain health care services to First Nations people. The province also provides services. The provincial government has responsibility for delivering health care services to all citizens of the province, and Section 88 of the *Indian Act* states that "general laws of application from time to time in force in any province are applicable to and in respect of Indians in the province". As a result of these factors, there has been confusion and disagreement about which level of government has the responsibility to provide health care services to First Nation populations and under what circumstances. The complexity and uncertainty results in service gaps and a lack of consistency in health care information and service provision, all of which contribute to the health burden of First Nations people.

The history of Aboriginal people in Canada has scarred Aboriginal communities and created difficult relationships with federal and provincial governments. The history of relocations, reserves, residential schools, environmental impacts, the *Indian Act*, discrimination, rupture of families, denigration of culture, loss of self-worth and loss of life compounds the malaise and explains poignantly the social dysfunction that has become widespread in many Aboriginal communities, (*Royal Commission on Aboriginal Peoples Report* (1996)).

On the other hand, there has been great progress in developing effective Aboriginal initiatives. For example, the Ontario government's Aboriginal Healing and Wellness Strategy has resulted in programs such as Aboriginal Health Access Centres, healing lodges, crisis intervention teams and the Aboriginal Healthy Babies and Healthy Children programs. In addition, initiatives such as the Aboriginal Long Term Care Strategy delivered by the Métis Nation of Ontario and the Federation of Indians Friendship Centres have been effective. Collaboration between Cancer Care Ontario and Ontario Aboriginal organizations to develop the Aboriginal Cancer Care Unit is another example. On a national level, the Healing Foundation and the National Aboriginal Health Organization have been established as a result of the recommendations of the *Royal Commission on Aboriginal Peoples Report* (1996).

Chapter Two

Methodologies

"Go to the people, they will give you the answers."

- Elder

2.0 METHODOLOGIES

Under the guidance of the Joint (Cancer Care) Ontario-Aboriginal Cancer Committee (JOACC), a Technical Advisory Committee (TAC) was struck to assist with and oversee this Needs Assessment. Carmen R. Jones, Manager of the Aboriginal Cancer Care Unit (ACCU) chaired the committee and Dr. Emily J. Faries, a renowned Aboriginal researcher, provided technical expertise and led the project team. Other members included:

- Germaine Elliott, Director of Health, Ontario Métis Aboriginal Association
- Janet Gordon, Executive Director, Sioux Lookout First Nation Health Authority
- John Garcia, Director, Prevention Unit, Cancer Care Ontario
- Dr. Loraine Marrett, Senior Epidemiologist, Surveillance Unit, Cancer Care Ontario

The first step in the study was to seek the support of Aboriginal communities. The Needs Assessment project received support through a resolution from the Chiefs of Ontario in 2001. Member organizations of the JOACC provided continuous support through their involvement on the committee. These measures enabled the project team to have access and co-operation from the many Aboriginal communities that participated in the assessment.

The Needs Assessment was carried out in accordance with the "*Ontario First Nations Regional Health Study*"[1], which articulates that research conducted in Aboriginal communities must meet the needs of the people. Earlier research and anecdotal evidence suggest that cancer services as they are currently provided do not meet the needs of Aboriginal people in Ontario. The study was designed to define those needs and identify gaps in cancer services, based on the perspective of Aboriginal people themselves.

The Needs Assessment is primarily qualitative in nature. The approach was designed to capture the thoughts and attitudes of participants regarding a multitude of issues related to cancer. Because the information collected is not easily quantifiable, the results have been carefully analysed and presented graphically and in narrative form. It is important to note that the findings are reflections of real life experiences of Aboriginal people regarding cancer. As such, the emerging themes are interlinked and may at times overlap.

Participants in the Needs Assessment were actively involved through interviews and group meetings. An important aspect of the project design was to provide feedback on the results to each community involved.

Both primary and secondary research was conducted to gather information for the Needs Assessment. The primary research was community-based and designed to generate qualitative information. Specific methodologies included:

1. Questionnaire surveys of First Nations communities and major urban Aboriginal organizations – 180 sent, 157 were returned;

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[1] *Ontario First Nations Regional Health Survey* -- Final Report Submitted to: The Chiefs in Assembly by The Research Group from Centre for Studies of Children at Risk Hamilton Health Sciences Corporation Faculty of Health Sciences, McMaster University in collaboration with the Technical Advisory Committee -- Chiefs of Ontario May 28, 1998

2. Individual and group interviews with cancer clients, family members of cancer clients, and local community health workers in 21 Aboriginal communities across Ontario – 229 individual participants;

3. Questionnaire surveys of cancer service agencies (including cancer care centres and their host hospitals, hospitals serving large Aboriginal populations, public health units and health access centres) – 78 sent, 50 were returned;

4. Group meetings with cancer service providers (including the JOACC) and interviews with physicians and traditional Aboriginal healers – 72 individuals;

5. Literature research from regional cancer centres, Health Canada, individual First Nations communities, and the Internet – 300 articles found, 103 annotated.

Each of the methodologies addressed specific topics, which are discussed further in the following chapters of this report. By gathering information from both Aboriginal people and cancer service providers, the research provided a broad understanding of critical issues. All the survey instruments were pilot tested prior to being applied in the field.

The Needs Assessment focused on an *Aboriginal perspective* of cancer care needs and services in order to determine and examine relevant programs, services, training, education, readiness and awareness required for culturally appropriate cancer care. Although some quantitative analysis was conducted, the emphasis was on qualitative research in Aboriginal communities.

2.1 The Objectives of the Needs Assessment

The primary objective of the investigation was to find out what Aboriginal people think, feel and believe about cancer and cancer services in Ontario, and to hear their stories. In particular, the Needs Assessment aimed to:

1. Determine how Aboriginal people in Ontario view cancer (understanding of what cancer is, and attitudes toward cancer);

2. Explore the awareness of cancer issues in Aboriginal communities, including knowledge of the cancer care system, including: prevention, early detection, treatment options (including traditional Aboriginal options);

3. Identify cancer care service priorities of Aboriginal people and communities, and to identify service gaps;

4. Investigate how Cancer Care Ontario Regional Centres (CCORs) and other cancer service providers are reaching out to Aboriginal communities, and how Aboriginal communities are linking/networking with cancer service providers;

5. Determine how Aboriginal people assess the cultural appropriateness and sensitivity of cancer services;

6. Explore the issues affecting the readiness of Aboriginal communities to receive and

implement cancer services;

7. Identify issues surrounding the use of tobacco, including traditional Aboriginal tobacco use and smoking cessation; and
8. Conduct a detailed review of the literature that addresses cancer and Aboriginal people to create a research resource for the ACCU and to identify research gaps.

2.2 Community Questionnaire

The community questionnaire survey was distributed to all First Nations in Ontario, as well as major Aboriginal health service providers in urban centres. It was faxed out, and extensive follow up was conducted. One hundred and eighty (180) questionnaires were distributed, and 157 questionnaires (87.2%) were completed and returned (see Appendix A for the text of the questionnaire).

The 157 Aboriginal communities included remote First Nation communities, rural First Nation communities, and Aboriginal (Métis, rural and urban) communities[2]. Throughout the Needs Assessment Report these are distinguished as "remote", "rural", and "urban Aboriginal" communities. There were:

- Thirty-two (32) remote First Nations (isolated and fly-in communities);
- Eighty-four (84) rural First Nations (road accessible communities), including 9 communities that are located near urban centres;
- Forty-one (41) Aboriginal community organizations that service Aboriginal people living off reserve, primarily in urban settings.

2.3 Community-Based Interviews

The "Community-Based Interviews" sections of this report provide the analysis of data from community-based interviews and discussion groups with 229 participants in 21 First Nation and Aboriginal communities.

Discussion groups and interviews were held with each target group, including: Aboriginal cancer clients, family members of Aboriginal cancer clients, and health workers who serve Aboriginal people. Permission was obtained from the Chief and Council in each First Nation before proceeding with the interview schedule. In urban centres, Aboriginal health organizations were asked to host the process. Staff of the community health centres set up individual interviews and discussion groups in accordance with preferences expressed by the participants. A team of experienced Aboriginal field facilitators conducted the interviews.

Because the interview and discussion group questions asked for personal beliefs and stories about cancer care and treatment, the facilitators provided each participant with supportive care contacts at the end of the session. Supportive care counsellors at the regional cancer centers and Aboriginal health organizations were notified of the potential for calls resulting from this process, due to emotional, unresolved or difficult issues that may be raised.

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[2] Urban Aboriginal communities include community organizations serving non-status Aboriginal people, Status Indians off-reserve and Métis organizations.

Each interview was audio taped and transcribed into text (one Microsoft Word document per individual or discussion group interview), in order to enable analysis by QSR NVivo, a qualitative data analysis program. A member of the consulting team, specializing in QSR NVivo, met with the transcriber to ensure the setup of the transcribed documents would facilitate the data analysis process. Accordingly, the attributes (region, community, type of respondent, and type of interview) of each interview were coded within the text of each interview, and codes were incorporated into the title of each document for easy identification. Once complete, the 130 transcribed documents were programmed into QSR NVivo for content analysis.

Prior to embarking on the data analysis process, consultants met with the community facilitation team and the project leader. The fieldwork process was discussed, and the interview team identified major themes that arose from responses to each question. The results of this meeting were used as a starting point to identify the "key themes" that formed the basis for quantifying responses for each question and participant group.

The documents were coded in two phases. First, based on an initial analysis of the contents of each interview, key response categories were developed for each question. Each interview was then further analyzed and coded according to detailed content of the responses to each particular question.

NVivo made it possible to quantify the types of responses that were received from interviewees of each target group, as well as from each community and within each of the seven regions across Ontario. To illustrate the results, graphs are provided. Only the collected results are presented in this report. Differences among types of interviewees, regions and communities are noted only when relevant.

The calculation of frequencies has been based on the following formula:

$$\frac{\text{Total number of respondents citing each category of response}}{\text{Total number of interview participants (i.e. 229)}} \times 100$$

Throughout the report, the term "Base" refers to the total number of interviewees (229), whether they responded individually or as a member of a discussion group. "N" represents the number of responses to each question.

The analysis of results is slightly negatively skewed across the board, since not all interviewees were asked, nor responded to, all of the questions. Furthermore, in many cases, respondents gave multiple responses to each question. Therefore, the results will rarely total 100%. Appendix C includes an overview of the responses by question and graphic summaries of the responses by type of interviewee.

The 21 communities were randomly selected using a formula designed to ensure the results reflected the whole Ontario Aboriginal population. Three communities were selected from each of seven geographic regions. In each region, one large (more than 500 members) First

Nation community, one small (less than 500 members) First Nation community, and one Aboriginal community (Métis, rural, or urban) were selected. The selected communities were as follows:

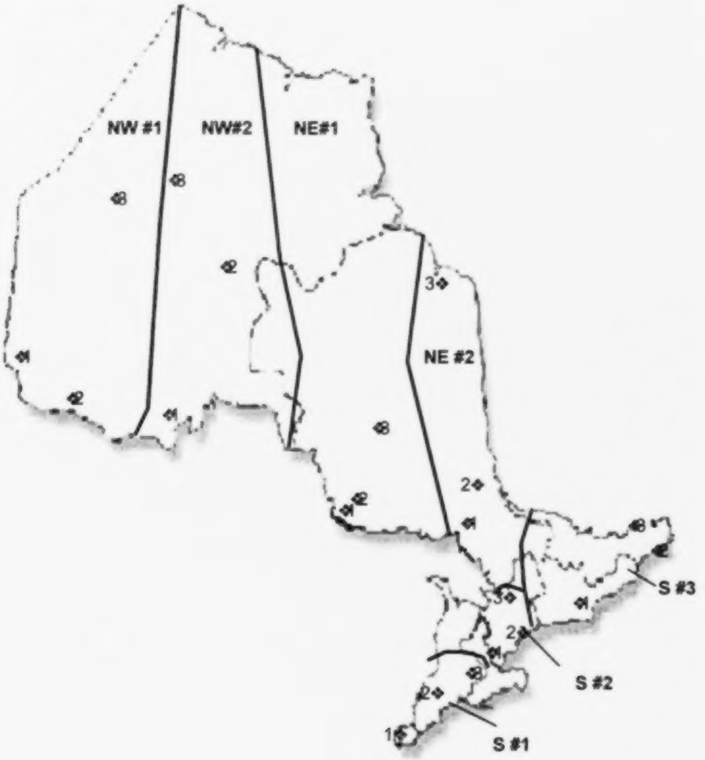
First Nations Communities

- Alderville First Nation
- Brunswick House First Nation
- Chippewas of Georgina Island
- Delaware First Nation
- Eabametoong First Nation
- Kingfisher Lake First Nation
- Mohawks of Akwesasne
- Moose Cree First Nation
- North Caribou Lake First Nation
- Ojibways of Batchewana
- Oneida of the Thames
- Shoal Lake #40 First Nation
- Six Nations of the Grand River
- Temagami First Nation

Aboriginal Communities

- Fort Frances
- Iron Bridge
- Ottawa
- Sudbury
- Thunder Bay
- Toronto
- Windsor

Aboriginal Cancer Care Needs Assessment
Random Selection of Communities (21)



Northwest #1
1. Shoal Lake #40 (228)
2. Fort Frances
3. North Caribou Lake (704)

Northwest #2
1. Thunder Bay
2. Eabametoong (1076)
3. Kingfisher Lake (374)

Northeast #1
1. Iron Bridge
2. Ojibways of Batchewana (737)
3. Brunswick House (127)

Northeast #2
1. Sudbury
2. Temagami First Nation (203)
3. Moose Cree First Nation

South #3
1. Alderville (283)
2. Mohawks of Akwesasne (7,834)
3. Ottawa

South #2
1. Six Nations of the Grand River
2. Toronto
3. Chippewas of Georgina Island (171)

South #1
1. Windsor
2. Delaware First Nation (235)
3. Oneida of the Thames (713)

There were 229 people interviewed in the 21 communities across Ontario, in both individual interviews and discussion groups. In total, the sample of 229 participants included:

- 54 Aboriginal cancer clients;
- 80 family members of Aboriginal cancer clients; and
- 95 health workers who provide health care to Aboriginal communities.

2.4 Service Providers' Questionnaire

Participants of the cancer service providers' questionnaire survey consisted of Cancer Care Ontario Regional Cancer Centres (RCC), the Canadian Cancer Society, public health units, host hospitals, and hospitals located in areas with large Aboriginal populations. Questionnaire surveys were sent out to 78 services providers and a total of 50 (64.1%) responded. The respondents were service providers engaged in cancer prevention, treatment, and aftercare.

The questionnaire sought information about:

- types of services provided;
- services offered specifically for Aboriginal clients;
- ways in which the provider reaches out to Aboriginal people;
- how the provider ensures that Aboriginal people have access to and are aware of cancer services;
- culturally relevant materials on cancer that they either produce or distribute;
- how the provider creates awareness of cancer specifically to Aboriginal people;
- tobacco-related programs within their local Aboriginal communities;
- other programs related to cancer prevention specifically for Aboriginal people;
- gaps in cancer services for Aboriginal people, and input on how their needs may best be met;
- other plans to deliver cancer-specific programs for Aboriginal people;
- information about other agencies providing cancer services that they may be aware of;
- any research, studies, or data collection in progress.

The survey questionnaire is included in Appendix A of this report.

2.5 Service Providers' Discussion Groups and Interviews

Discussion groups were held at eight established and two developing Regional Cancer Centres (RCC) in ten different locations throughout Ontario:

Established RCCs

- Thunder Bay
- Sudbury
- Ottawa
- Kingston
- London
- Windsor
- Hamilton
- Toronto (Sunnybrook)

Developing RCCs

- Sault Ste. Marie
- Kitchener (Grand River)

A JOACC discussion group was held. In addition to the 11 discussion groups, two traditional Aboriginal healers and three physicians who work specifically with Aboriginal people were interviewed. A total of 72 service providers participated in the discussion groups and/or interviews.

Prompted with a basic list of topics, the service providers held discussions on:

- access to medical personnel and services;
- jurisdictional issues and regional differences;
- transportation;
- coverage;
- cancer prevention;
- diet and lifestyle;
- smoking cessation/prevention;
- links with Cancer Care Ontario Regional Cancer Centres;
- gaps and priorities in cancer care and services for Aboriginal people;
- Aboriginal specific services that they would like to see;
- Aboriginal perspectives on cancer and their own perspectives on cancer;
- traditional Aboriginal healing;
- alternative treatments;
- prevention;
- cultural appropriateness of services; and
- education and training.

In addition, the service providers offered additional comments and success stories encountered through their work. The discussion questions are included in Appendix A of this report.

2.6 Secondary Research

The objective of the secondary research was to identify Aboriginal-specific literature on cancer prevention, treatment, incidence and mortality in order to;

- support ACCU policy and program development;
- identify gaps in the literature and research needs; and
- provide a research tool for academic researchers and a resource for community members interested in cancer.

The secondary research consisted of a literature review, which supplemented the Needs Assessment findings and the sources for which are summarized in Appendix D. The literature research was conducted using Health Canada resources, information at cancer centres and through the Internet. The literature includes scientific and academic journal articles as well as a number of community education and communication tools and reports.

An annotated bibliography of many of these resources has also been produced and is available through Cancer Care Ontario. It is the first comprehensive bibliography on the subject of cancer and cancer care among Aboriginal people in Ontario. It is meant to be useful to lay researchers and community health workers. Newly diagnosed clients, family members, clinicians and specialists alike will find the document useful. The listings and annotations are informative and comprehensive, leading the reader to more specific and detailed sources.

Chapter Three

Aboriginal Views of Cancer

"In fact, there is no Cree word for cancer because the disease is so new to us."

– Family Member

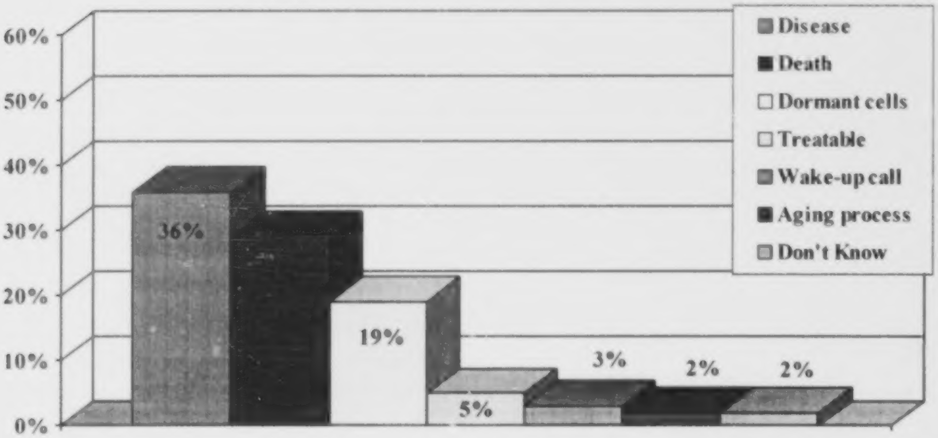
3.0 ABORIGINAL VIEWS OF CANCER

3.1 Community Interviews

3.1.1 What is cancer?

One objective of the community interviews was to determine how Aboriginal people view cancer. Interviewees were asked to describe their beliefs about what cancer is.

Figure 1: Beliefs About What Cancer Is



Note: Percentages may not sum 100 due to multiple responses and non-response. Base = 229 N = 222

36% (**83** respondents) described cancer as a **disease, sickness or growth.** The main idea expressed by respondents in this group was that cancer is a disease involving the abnormal growth of cells. Others thought the causes were more internal or just a matter of chance.

29% (**67** respondents) said they consider cancer an **incurable, terminal, death sentence**; that the mere mention of the work "cancer" strikes fear into their hearts. A few felt that evil forces were involved. It appears that most people in this group did not believe that cancer could be beaten.

19% (**44** respondents) viewed cancer as **cells, genes, or a virus lying dormant** in everyone's body; they believed that cancer could suddenly become active and begin to cause abnormal growth in cells that can be set off by triggers such as stress or germs. Others felt that cancer is a weakness in a person's immune system. Others expressed a more fatalistic view, considering it inevitable that some people will get cancer.

5% (**11** respondents) respondents said they **did not really know** what cancer is.

3% (**8** respondents) described cancer as **a treatable disease** that is survivable.

2% (**5** respondents) said that cancer provides **a wake-up call to value life**. Most referred to the fact that cancer survivors are strengthened through their battle with the disease.

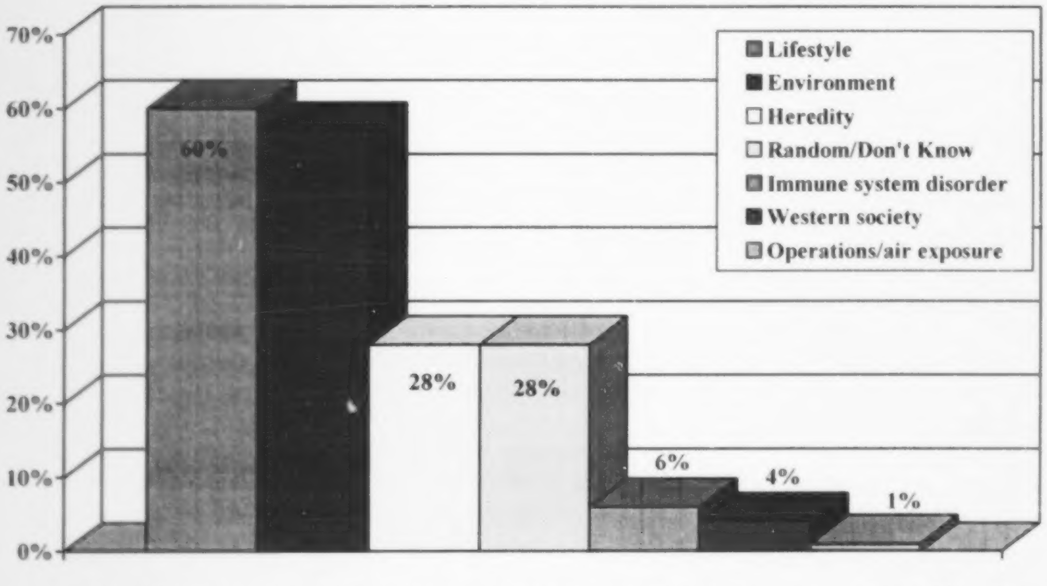
2% (**4** respondents) saw cancer as an inevitable **part of the aging process**. They believe that as a person grows older, the risk of getting cancer increases, particularly as the immune system weakens.

3.1.2 Where does cancer come from / why do people get it?

Study participants were asked two questions: "Where do you think cancer comes from?" and "Why do you think people get cancer?" Because these questions are meant to examine two aspects of the same question, interviewers often asked the two together.

The majority of respondents recognized that the cause of cancer is not a simple issue, and most identified more than one factor in their response.

Figure 2: Beliefs About Where Cancer Comes From



Note: Percentages may not sum 100 due to multiple responses and non-response. Base = 229 N = 419

60% (**137** respondents) said that **lifestyle factors** play a major role in causing cancer. Most respondents in this group listed numerous factors, the most common of which were smoking, poor diet, stress, and lack of exercise. Smoking appears to be widely recognized as a serious cancer risk. Respondents frequently mentioned a change in Aboriginal diet from traditionally eating low-fat natural foods to now eating more highly processed fatty foods, and lack of exercise in the modern lifestyle, as factors. Negative emotional factors such as unresolved anger and stress were also thought to trigger cancer. Some felt that bodily injuries such as bruises could turn into cancer.

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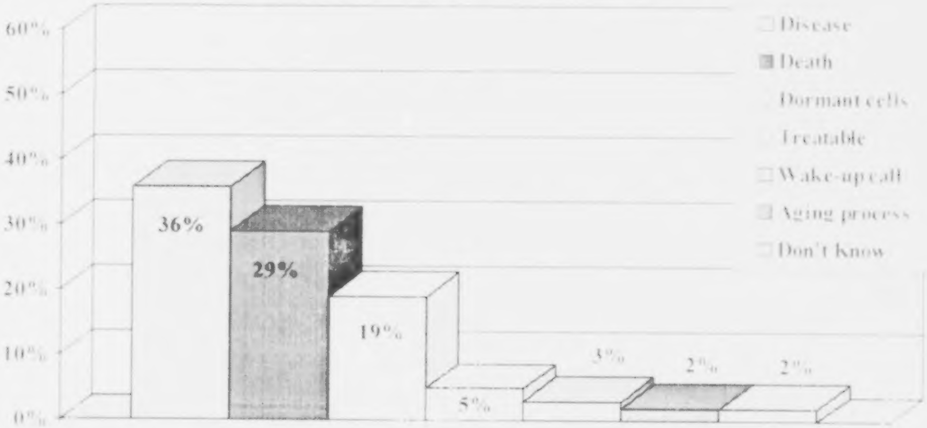

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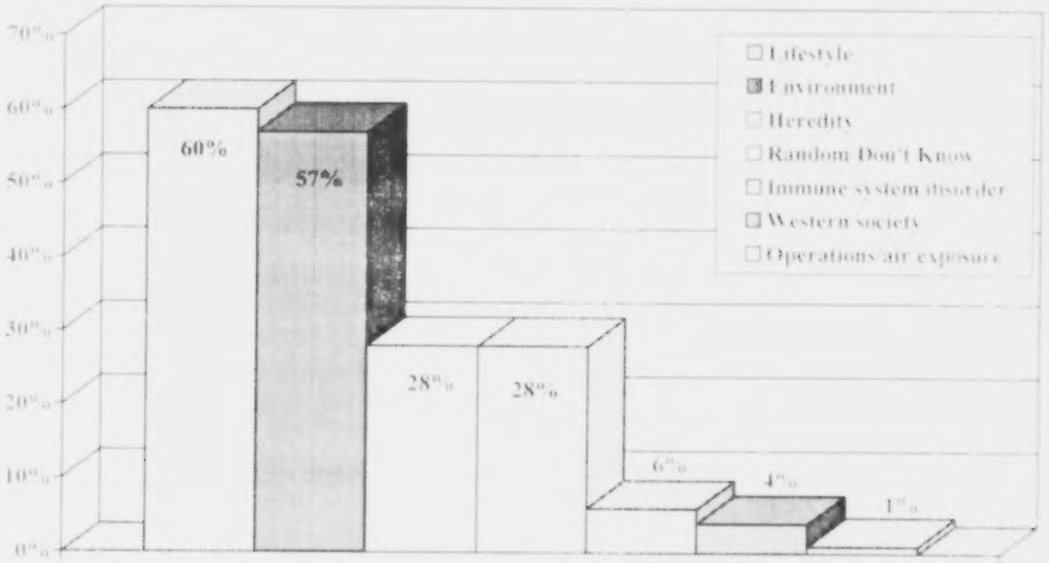

Note: Percentages may not sum 100 due to multiple responses and non-response. Base = 229; N = 119

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57% (130 respondents) cited **environmental factors** as major contributors to the incidence of cancer such as pollution, food additives, herbicides/pesticides, acid rain, industrial waste/pollution and water.

28% (65 respondents) **did not know**. Whereas health workers were more likely to provide informed scientific explanations for cancer, significant numbers of cancer clients and family members said they have no idea where cancer comes from. A number of comments suggested that those who do not know are more likely to see cancer as terminal. Several respondents commented on the fact that cancer can hit anyone, even those with healthy lifestyles. A few respondents felt that those who get cancer are destined to get it.

28% (63 respondents) named **heredity** as a major cause of cancer. Cancer clients were the most likely to comment upon the genetic factor.

6% (13 respondents) thought that cancer stems from an **immune system disorder**. To the majority of respondents in this group, stress plays a major role in weakening the immune system, which makes a person's body vulnerable to cancer.

4% (9 respondents) believed that cancer was **introduced to the Aboriginal community by Western society.** Several commented that cancer is one among a spectrum of many diseases introduced to Canada by European immigrants. Food additives brought in by Europeans were also thought to play a role.

1% (2 respondents) believed that **surgery exacerbates cancer by exposing the cancer tumors to air.**

3.2 Service Providers' Interviews

Cancer service providers were asked to discuss their observations about **Aboriginal people's perspectives on cancer**. The groups who offered observations discussed a variety of topics including:

- reluctance to discuss cancer/seek assistance;
- fatalistic attitude toward cancer;
- value placed on the concept of destiny;
- the effects that personal issues and experiences common among Aboriginal people have on acceptance of cancer, treatment, and pain management;
- causes of cancer;
- traditional teachings and holistic healing;
- spirituality; and
- no difference in regards to perspective.

3.2.1 Reluctance to discuss cancer or seek assistance

Perspectives seemed to vary among age groups and were often based on peoples' beliefs, rather than factual information. One group noted that young Aboriginal people seem better-educated and more assertive about cancer than older people, who appear to be more private and unwilling to discuss the disease. With regards to breast screening, another group observed that women are unlikely to come for screening either because they do not want to have a part of their body removed or because they fear that screening will bring the cancer upon them.

One discussion group described people's fear of the spreading of the disease by talking about it too much, and how their lack of understanding impedes their ability to cope with the realities of cancer.

3.2.2 Fatalistic attitude

Fear of cancer appears common among Aboriginal people. Service providers testified to a **fatalistic attitude** related to cancer among the Aboriginal clientele. Many believe that cancer is incurable, or a disease that kills from inside. There is a stigma based on the thought that *"No one ever lived after cancer, they just went away to die"*. This stigma needs to be openly addressed. Two physicians also commented on the fact that people do not talk about cancer; and their strong fear of the disease appears to be fatalistic.

3.2.3 Destiny

Service providers often witness a quiet acceptance among Aboriginal people that *"Life will unfold in the way it was meant to be"*. The concept of **destiny** was identified by three of the service provider discussion groups, which were situated in different locations across Ontario. They observed a general attitude that whatever happens will happen, and cancer is a natural process for those who are diagnosed with it. One participant discussed the frustration of physicians who focus on treatment and success that have clients refuse treatment because they think that illness and death is their fate. Another group linked the acceptance expressed by Aboriginal people to spirituality and beliefs. In this group, there was a lengthy discussion about the fact that some people simply accept that they are going to die, sometimes to the point of humour, where one Elder even joked about the possibility of having to shave her head. Some Aboriginal people simply accept the diagnosis and prepare for death.

3.2.4 Impact of the Aboriginal reality on attitudes

Service providers talked about the **unique experiences of Aboriginal people,** and how they play a role in their response to cancer and cancer care. One group discussed at length their clients' failure to disclose information about their cultural backgrounds, personal issues, or the pain they may be experiencing. Failure to do so affects the actions of health practitioners, who report having to ask very direct questions and encourage patients to call. Other groups reported similar findings.

3.2.5 Attitudes toward treatment

Cancer service providers commented on **attitudes toward cancer treatment**. They noted that elders will not contact medical personnel, but their family members will. They note that some patients accept cancer as the way they will die. One described a patient who had a difficult time with chemotherapy because he did not think putting poisons in him was proper. Another service provider added that patients, especially more traditional Aboriginal people, seem to fear navigating a foreign system.

3.2.6 Causes of cancer

One group discussed messages they were getting from Aboriginal clients about **causes of cancer**. One cancer patient who was an elder felt that cancer came from pollution. He believes that people get cancer from animals that live off the land.

3.2.7 Traditional ways

One participant pointed out that only certain families have retained traditional ways and beliefs, meaning that only a few people have access to **traditional teachings and medicines**. When it comes to cancer, they look toward the community because they need a supportive, caring place. **Spirituality** was noted as a common theme and the belief in holistic care was brought forth.

Some participants noted that they have witnessed First Nations people who are diagnosed with cancer turning to traditional medicine. Having participated in sweats and healing ceremonies, they explained how it helped patients through their illness. Some were healed, while others went into remission. They noted that many Aboriginal people believe that people's minds, feelings and perceptions have power.

Two traditional healers offered their perspectives on cancer. The first pointed out that, *"A lot of cancers can be beaten; cancer comes when we do not look after ourselves"*. Participants from other interview sessions agreed with this view.

One traditional healer said, *"I have come to know with some considerable understanding of our belief systems and our role in Creation, and the consequences of human behaviour ... the human being has been given mind choice and intellect. The mind is very powerful and can do many enormously good things. We can choose to do things that are destructive to the environment and to ourselves"*. He gave an example about the destruction to the Earth, and how we need to change this type of behaviour. He explained the human connection to the earth as: *"From our traditional understanding, our body is such a special thing that it is given everything it needs to heal itself. Similarly, we are given things in the natural world which are medicines"*.

Service providers noted the exceptionally supportive nature of Aboriginal families.

3.2.8 Spirituality

One discussion group, comprised of First Nations members, offered further insight to Aboriginal perspectives on cancer. Most of their comments related to the importance of spirituality. Members of this group felt that when a person gets physically sick, their spirituality grows stronger. They point out that many people have found comfort in traditional medicine when they are diagnosed with cancer.

Members of another discussion group pointed out that every human being has a spiritual design. Having limited experience with Aboriginal patients, they inadvertently pointed out more similarities than differences to other cultures. This group feels that the spirituality of all cancer patients needs to be addressed, not just that of Aboriginal people.

3.2.9 No differences

It should be noted that there were mixed reactions among service providers about Aboriginal perspectives on cancer. One participant commented that, *"It seems like Aboriginal people have similar issues to immigrants"*. In contrast, two other groups reacted that they **don't think Aboriginal people view cancer differently from anyone else**. They see cancer diagnosis as a shock for everyone, not just Aboriginal people.

One group observed that the only difference they see is that Aboriginal people have more competing social and health problems to deal with. It may be more difficult for Aboriginal people who do not have a doctor to deal with cancer, but it was also observed that Aboriginal people do not seem to get as upset that they do not have a doctor. Service providers noted a big difference between on-reserve and off-reserve residents, with some being more traditional in their beliefs. Viewing cancer as a life-threatening mystique, one discussion group talked about the fact that a diagnosis of cancer often guides people into some form of **spirituality** whether it be Christianity or traditional.

3.3 Secondary Research

Investigations into the causes of cancer, for the most part, supported the interviewees' perception. People are concerned about transitions in diet, environment, lifestyle (alcohol and tobacco consumption) and being around or talking about cancer. Environmental or cultural conditions, hormones and genetics, exposure to harmful carcinogens, and ultraviolet rays were also seen as causes of cancer. The medical community is beginning to look at the extent to which these factors influence neoplastic growth, and in some cases, which anatomic sites are affected the most.

Concern over the change from a traditional Aboriginal diet to contemporary foods was discussed by some of the studies reviewed. Clinical research identified the Alaskan Aboriginal diet as a variable in the development of nasopharyngeal carcinoma (Lanier, et al., 1980), initiated the study of dietary variation among Aboriginal people. A study investigating cancer incidence and mortality among Aboriginal people in the Sioux Lookout Zone also considered the change in diet as a contributing factor (Young & Frank, 1983).

In research on site-specific cancers, dietary transition was identified as accessory to *"substantial increases in colon and rectum cancer, as well as kidney and gall bladder cancers among Native women."* (Marrett, 1998). Attention to diet, among other variables, was addressed by Cobb & Paisano (1988) in their study on Native American cancer mortality patterns. The following year, Norsted & White wrote about diet as a factor for changes in proportional cancer incidence among Native Americans of western Washington.

In 1989, Mahoney et al. expressed a desire to observe how dietary practices among the Seneca contribute to cancer mortality patterns in adults. Along with lifestyle, alcohol and tobacco consumption, Gillis et al. (1990) attributed low post-diagnosis survival rates to changes in diet among Aboriginal people in Saskatchewan.

Diet was among a list of five determinants for future cancer trends identified by Seivers and Fisher in 1983. Since 1993, there have been four National Cancer Institute projects in the United States, each conducting cancer intervention research specifically related to tobacco and dietary risk factors among American Indians (Burhansstipanov, 1993). Mahoney and Michalek (1999) describe the incorporation of awareness of dramatic changes in diet for American Indians and Alaska Natives in their "Lessons for Cancer Educators".

Investigations into cancer etiology often examine and identify factors such as environment, lifestyle (alcohol and tobacco consumption), and genetics as risk factors. Authors who have used these factors as variables in their studies include Lanier, et al., 1980; Seivers and Fisher, 1983; Young, 1983; Hildes and Shaefer, 1984; Lynch, et al., 1985; Cobb and Paisano, 1988; Robinson, 1988; Horner, 1990; Mahoney and Michalek, 1991 and 1999; Bleed, et al., 1992; Clarke, et al., 1992; Gaudette, et al., 1993; Weiner, 1993; Sugarman, et al., 1994; and Brant, (undated).

Being around or talking about cancer was also mentioned as a possible factor. Such reluctance to discuss the disease has in fact been written about by Michielutte, et. al., 1994; Schanche Hodge, et al., 1996; Strickland, et al., 1996; Burhansstipanov, 2000; and Opie, (undated). They identified the reluctance to talk about cancer as a barrier to participation in screening programs, and looked toward culturally sensitive approaches such as talking circles to remedy the inhibition. In their work among the Yakama of Washington, Strickland, et al. (1996) found that discussions of death and dying would not be a successful motivator in approaching cervical cancer prevention. The study also found that women were particularly reluctant to talk about cancer.

In 1983, Seivers and Fisher examined issues such as the susceptibility to certain carcinogenic effects, uranium mining, the degree of American Indian heritage, and rapid changes in environmental and cultural conditions as determinants for future trends. Two studies associated Navajo exposure to uranium as a cause for lung cancer (Gottleib and Husen, undated; and Samet, et al., 1984). Weiner (1993) identified pollutants as a cause. Pollution and exposure to ultraviolet sunrays were also mentioned as a cause in the Association of Iroquois and Allied Indians' video, *Healing Bridges – Cancer Care Concerns* (1996).

Community participants raised concerns about the health impacts of exposure to asbestos, hydro defoliants, transmission towers or microwaves. However, the literature search did not find studies to specifically address these issues among Aboriginal people.

3.4 Summary of Findings

While views of cancer are not universal among Aboriginal people, there is a generally pessimistic attitude toward the disease. One third of participants believe that a diagnosis of cancer is a death sentence, while only three percent (3%) identify that they think cancer can be treated. Many Aboriginal people believe that cancer is inevitable, they feel it is a matter of genetics or fate, or primarily caused by forces outside their control, such as the environment, toxins in the food they eat, or the quality of life imposed on them by the reserve system.

Observations of the service providers confirm that Aboriginal people tend to have a fatalistic view of cancer. They also identified reluctance among Aboriginal people to discuss cancer and reach out for assistance. Service providers note that only a few families appear to follow traditional ways, and only a few Aboriginal people have access to traditional healing. However, spirituality and a distinct Aboriginal world view are often present. Some service providers noted that traditional practices often have a positive impact on the patient outcome.

Recent research reveals changing patterns in the types of cancer prevalent in the Aboriginal population and the rates of incidence and survival (Marrett, 2002). There have been studies that examine diet, lifestyle and genetics as factors in Aboriginal cancer. Environmental carcinogens and ultraviolet exposure in the Aboriginal population has also been considered. The issue of reluctance to discuss cancer has also been studied. Overall, there is a shortage of comprehensive research involving large population samples.

Chapter Four

Traditional Healing

"The gap between western and traditional beliefs is the biggest challenge. For every race that walked on the face of this planet, he/she has a way of life."

- Traditional Healer

4.0 TRADITIONAL HEALING

4.1 Community Questionnaire

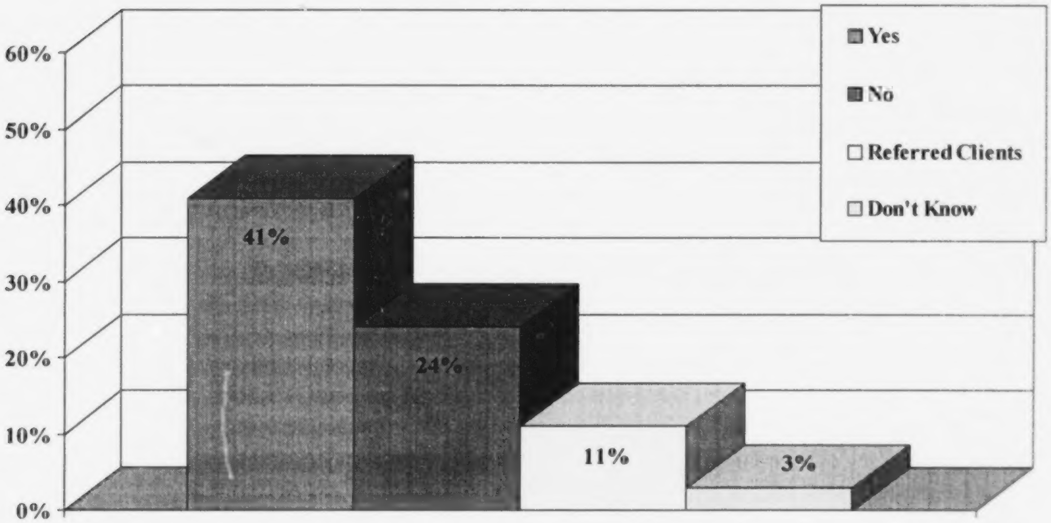
Access to traditional healing in the Aboriginal community is very low; for example, only 9% of remote communities have a resident traditional healer while 31% of rural communities have traditional healers. 44% of urban Aboriginal communities state that they have access to traditional healers.

4.2 Community Interviews

4.2.1 Have cancer clients consulted with traditional Aboriginal healers?

Interviewees were asked whether they, their family members or their clients had consulted with Aboriginal healers.

Figure 3: Consultation With Traditional Healers



Note: Percentages may not sum 100 due to multiple responses and non-response. Base = 229 N = 181

41% (**93** respondents) reported that they have consulted with traditional healers. Additional comments indicated that Aboriginal cancer patients go to western doctors for diagnosis and subsequently seek out a traditional healer for treatment. There was also some indication that patients prefer to keep information about their traditional treatments private.

24% (**56** respondents) said they have not consulted with traditional healers. The majority (48) of these respondents offered one or more reasons why they did not seek out Aboriginal healers (See Figure 5.)

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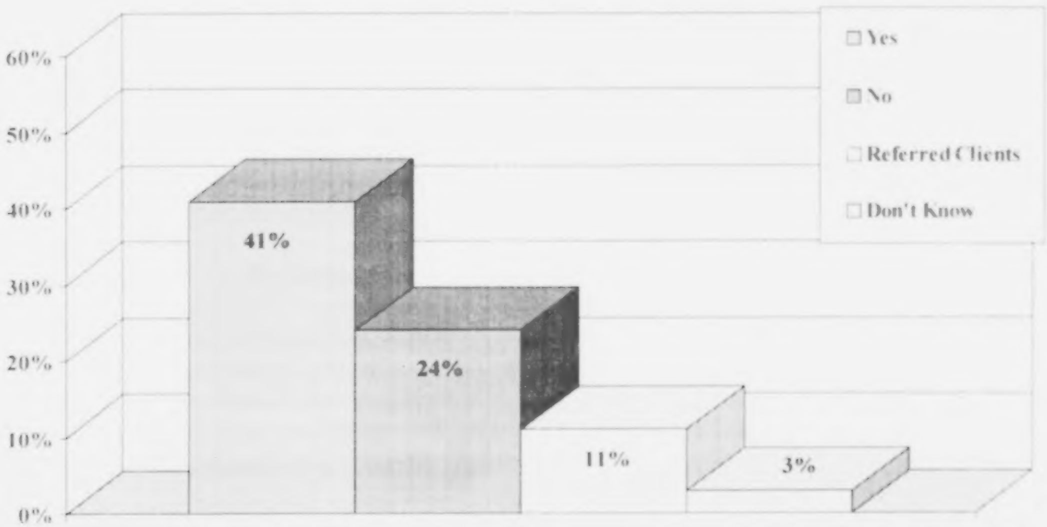

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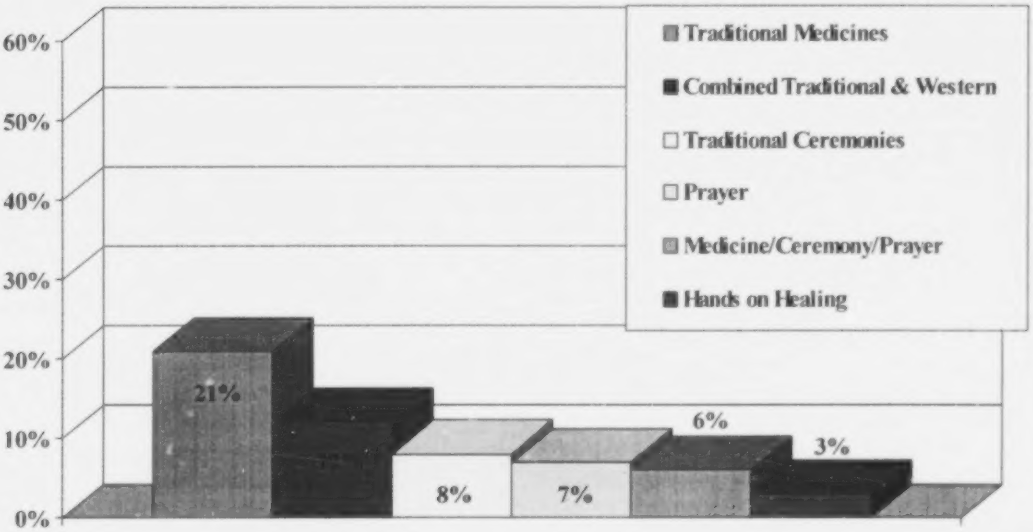
11% (**25** respondents) said they **did not know.** Some truly did not know if their clients or family members had consulted with traditional healers. Others preferred to keep that information confidential.

3% (**8** respondents) were health workers who had **referred clients to Aboriginal healers**.

4.2.1 Types of traditional treatment

Those who said they, their family members, or their clients had consulted with Aboriginal healers were asked what kind of treatment they received.

Figure 4: Types of Traditional Treatment Received



Note: Percentages may not sum to 100 due to multiple responses and non-response. Base = 229 N = 133

21% (**48** respondents) described **traditional medicines** that they had been given. Most frequently, the medicine involved using natural products such as herbs, barks, or berries to make tea. Some ingredients that were specifically mentioned include: herbs, tamarack bark, cedar boughs, dandelion, bear grease, beaver castor, berries, roots and spring water. However, in almost every case, only the healer knew the exact contents of the medicine given to cancer clients. A few people described herbal face washes, while others referred to salves of bear grease or prickly ash.

12% (**28** respondents) **combined traditional and western treatments**. Most respondents in this group saw the two types of treatments as being complementary. Some cancer clients said that they would try traditional treatments if western medicine failed. Several commented that they were afraid of negative reactions from mixing two types of treatments.

8% (**18** respondents) described cancer clients' participation in **traditional ceremonies.** These ceremonies usually combined a number of elements, such as smudges, pipe ceremonies, dances, drumming, singing, and prayer. The special ceremonies were explicitly mentioned and some people spoke about sweat lodges.

7% (**17** respondents) said that **prayer** was the most important component of their traditional treatment.

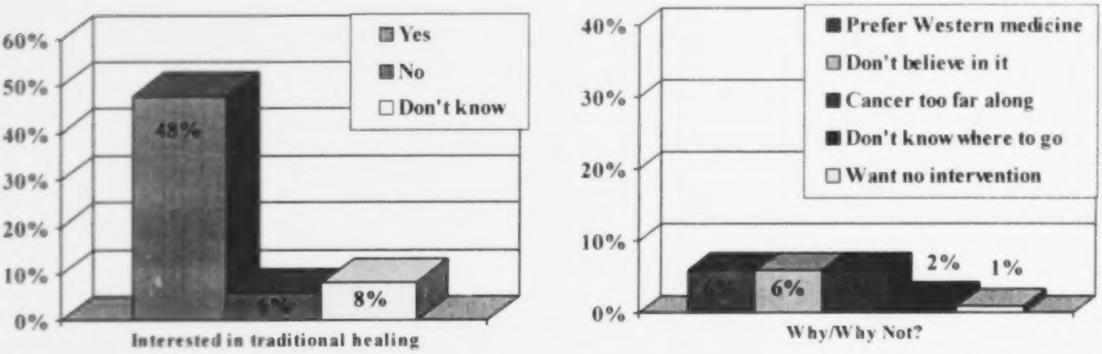
6% (**14** respondents) spoke about a **combination of various kinds of traditional treatments** such as medicines, ceremonies, and prayer.

3% (**8** respondents) described **hands on healing**. Most respondents in this group described massage and touch therapy, fasting and healing circles supervised by traditional healers.

4.2.2 Interest in traditional healing

Participants were asked if they had an interest in traditional healing methods, even if they had not consulted an Aboriginal traditional healer.

Figure 5: Interest in Traditional Healing



Note: Percentages may not sum to 100 due to multiple responses and non-response. Base = 229
N=142 *N=47*

48% (**110** respondents) stated that they were interested in traditional healing.

6% (**14** respondents) said they were not interested. Reasons cited corroborate the findings discussed in Section 4.2.1 (individuals either don't believe in traditional healing, or they prefer western medicine).

8% (**18** respondents) **did not know** whether or not they were interested in traditional healing. Most in this category said that they did not fully understand traditional healing. Some

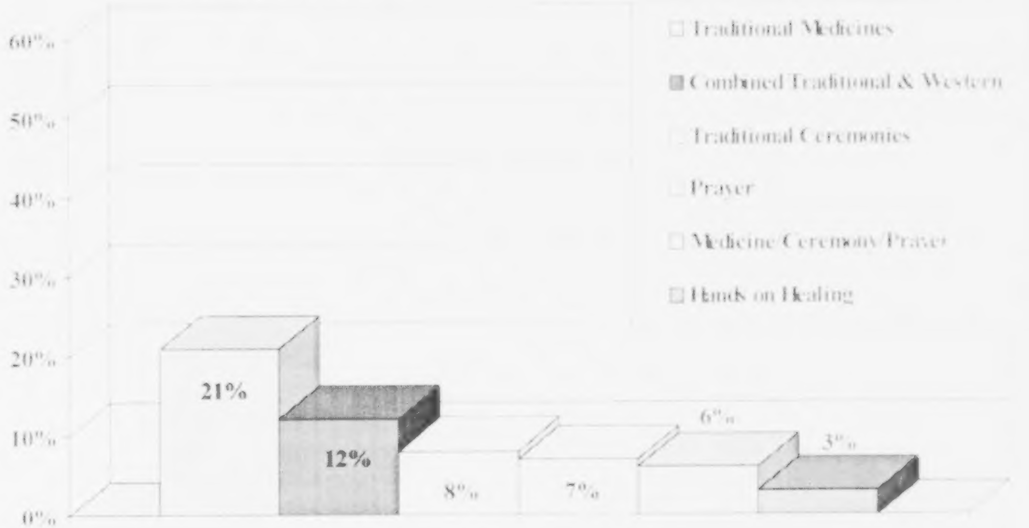
11% (**25** respondents) said they **did not know.** Some truly did not know if their clients or family members had consulted with traditional healers. Others preferred to keep that information confidential.

3% (**8** respondents) were health workers who had **referred clients to Aboriginal healers**.

4.2.1 Types of traditional treatment

Those who said they, their family members, or their clients had consulted with Aboriginal healers were asked what kind of treatment they received.

Figure 4: Types of Traditional Treatment Received



Note: Percentages may not sum to 100 due to multiple responses and non-response. Base = 229 N = 133

21% (**48** respondents) described **traditional medicines** that they had been given. Most frequently, the medicine involved using natural products such as herbs, barks, or berries to make tea. Some ingredients that were specifically mentioned include: herbs, tamarack bark, cedar boughs, dandelion, bear grease, beaver castor, berries, roots and spring water. However, in almost every case, only the healer knew the exact contents of the medicine given to cancer clients. A few people described herbal face washes, while others referred to salves of bear grease or prickly ash.

12% (**28** respondents) **combined traditional and western treatments**. Most respondents in this group saw the two types of treatments as being complementary. Some cancer clients said that they would try traditional treatments if western medicine failed. Several commented that they were afraid of negative reactions from mixing two types of treatments.

8% (18 respondents) described cancer clients' participation in **traditional ceremonies.** These ceremonies usually combined a number of elements, such as smudges, pipe ceremonies, dances, drumming, singing, and prayer. The special ceremonies were explicitly mentioned and some people spoke about sweat lodges.

7% (17 respondents) said that **prayer** was the most important component of their traditional treatment.

6% (14 respondents) spoke about a **combination of various kinds of traditional treatments** such as medicines, ceremonies, and prayer.

3% (8 respondents) described **hands on healing**. Most respondents in this group described massage and touch therapy, fasting and healing circles supervised by traditional healers.

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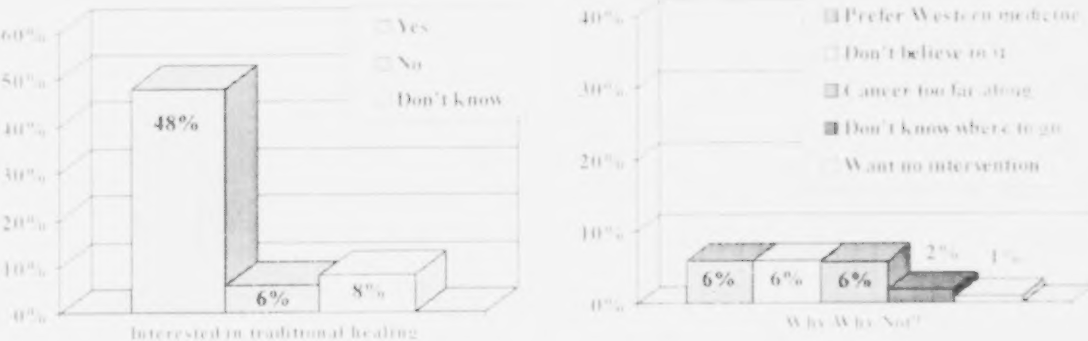

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8% (18 respondents) **did not know** whether or not they were interested in traditional healing. Most in this category said that they did not fully understand traditional healing. Some commented that if they knew more about traditional healing, they might be willing to try it.

4.2.3 Why or why not engage in traditional healing?

When asked why or why they are not interested in traditional healing, participants responded as follows:

6% (14) prefer western medicine.

6% (14) said they **did not believe in it.** Responses in some communities revealed a strong Christian presence and conflicting beliefs about traditional ways.

6% (13) said they, their family members or their clients may have wished to see a traditional healer, but their **cancer was too far along.**

2% (4) said they **did not know where to go.** Respondents stated that they did not know how to find healers.

1% (2) wanted no intervention.

4.3 Service Providers' Interviews

The service providers were asked to comment on **traditional Aboriginal healing.**

Three groups included participants who had witnessed the benefits of traditional healing. While one expressed their hope for the benefits of an Aboriginal healing lodge, others recognized the psychological benefits during palliative care. Others recommended that ceremonies, circles, and meditation be promoted. They noted the accuracy of the predictions that some traditional medicine people make, and how this has an impact on patients' acceptance of their treatment. The value of the holistic nature of traditional healing and the important role of the healers in helping to restore trust was also noted.

Service providers would like to see their clients be given the opportunity to make choices about their treatments and have access to traditional healers. Four of the groups thought that people should be informed immediately and given treatment options for both traditional healing and western medicine. One traditional healer pointed out that some Aboriginal communities do not have traditional healers, and assistance should be available to help people locate healers in other communities if they choose.

Service providers commented that some Aboriginal clients use traditional and herbal remedies alongside their physician's treatment, yet they do not always report it. They expressed concern about the possibility of contradicting medications. The basis for people's reluctance to talk about their traditional care was explained by the two traditional healers, who stated that it had been made illegal to practice healing and that some Aboriginal people are afraid to disclose their use of traditional healing methods.

Traditional healers would like to bring traditional healing back to the people, and would like to see western doctors show more respect and recognition towards traditional healers and medicine people. Many physicians are very resistant to the inclusion of traditional healers in patients' treatments because they do not understand traditional healing practices. Some physicians may have reservations because healers are not licensed to practice medicine. One physician expressed a desire for more open-mindedness regarding different spiritual and cultural issues.

4.4 Secondary Research

4.4.1 Aboriginal healing

In the context of traditional ecological knowledge, Knudtson and Suzuki (1992) explain the combined efforts of the scientific community and the wisdom of elders for answers to such diseases as cancer and AIDS. Methods of traditional healing, adherence to a well-balanced diet, and use of natural medicines are described in a number of articles, including the Association of Iroquois and Allied Indians' video *Healing Bridges* (1996), and the First Nations Breast Cancer Society's 1996 video, *Echoes of the Sisters.*

In the latter, they isolated the roles of traditional healer, radiologist, and spiritual elder, before discussing alternative medicines from both the traditional healer and medical doctor's perspectives. They emphasized the importance of the patient's need to feel comfortable with their medicine. A few authors wrote about the importance of balancing Aboriginal healing with contemporary care for the cancer patient. One such study among the Ojibwe of Minnesota, Elliot, et al. (1999) sought advice from traditional healers on cancer pain management.

> *"Working with traditional healers to address the pain in a way that combines the strengths of both cultures respects the traditions of American Indian/Alaska Native people, and may offer more complete management of the pain."* (Elliot, et al., 1999)

In 1987, Samet, et al. investigated cultural influences and reliance on traditional health care as factors leading to variations in stage at diagnosis, compliance with therapy and cancer survival among American Indians and Hispanics in New Mexico and Arizona. Wiggins, et al. (1993) pointed out that among the Navajo, Pueblo, and Apache of the same area, medicine people and traditional healers were still playing an important role in their health care provision. At present, the National Native American Cancer Survivors' Support Network (2001) in the United States, has resources on traditional healing available on their website.

A good example of how health care has evolved from traditional medicines and healing to contemporary health care structures, is a study by Robinson (1988). She describes how the Quebec Cree have undergone enormous change from the 18th century to the present, illustrating the contemporary reality of access to modern medical facilities from fly-in communities.

4.4.2 Types of traditional treatment

In the literature, information on traditional treatment covered a number of themes including ceremonies, family values, self-care, cancer awareness, sweat lodges, diet, healthy lifestyles, outlook, and having a holistic approach to healing. While discussed in the videos, no specific reference to natural herbs, medicines or remedies could be found. The importance of ceremonies was included in the California cervical cancer screening and prevention project described by Schanche Hodge, et al. (1996). The importance of family relationships for First Nations people was discussed by Opie and Hackenburg (undated) of the Ontario Breast Screening Program; Masi, et al., 1993; and Harvald, 1990. All authors considered the inclusion of family to be fundamental to Aboriginal healing.

The use of sweat lodges was encouraged by Strickland, et al. (1996) as an opportunity for elders to share messages with the family and to emphasize wisdom behind holistic approaches to cancer prevention. Emphasis was placed on messages that focus on staying healthy to pass Aboriginal culture on to future generations and how this can link with meeting community and individual needs.

Brant (undated) offered a section on traditional medicine in her chapter on 'Breast Cancer Challenges for Native American Women.' Brant explains how traditional women inter-relate spirituality with health in a holistic perspective, and concludes with the importance of finding a balance between Western and traditional medicines in the treatment of breast cancer for Aboriginal women. A series of four videos produced by the Denver Indian Centre in 1998 convey similar messages on breast cancer survival.

Significance of the holistic perspective of physical, mental, emotional and spiritual healing and wellness, and the concept that individual, family and community are viewed as inseparable were considered in strategies for Aboriginal cancer care efforts of the Joint Ontario Treatment and Research Foundation (OCTRF)/Cancer Care Ontario (1997). A similar discussion is also found in Cooper, et al. (1991).

4.5 Summary of Findings

There is a widespread desire to access traditional healing methods among the Aboriginal people. Some Aboriginal patients go to Western doctors for diagnosis, and then seek out a traditional healer for treatment; some turn to traditional methods if conventional methods fail. It is common for patients to participate in both conventional and traditional treatment at the same time. Traditional methods are felt to be particularly helpful with a patient's holistic well being, including spiritual needs and state of mind. Research has identified traditional healing as having a role in palliative care and pain management.

However, despite the desire for traditional care, access to traditional healing in Aboriginal communities is low, especially in remote communities. Fewer than 10% of remote communities and fewer than 33% of rural communities have access to traditional healers. When in unfamiliar urban centres for cancer treatment, many Aboriginal patients and their families report great difficulty in finding a traditional healer to help them.

For a variety of historical and cultural reasons, some Aboriginal clients do not tell their physicians that they are also taking traditional treatments. There is concern among both the community members and service providers that this "hidden" use of traditional remedies could lead to problems such as negative drug interactions. While there is literature that supports the value of traditional healing methods, particularly in supporting the patients' spiritual and emotional needs, there is a lack of specific information about the components of traditional remedies or practices to prevent cancer. Both western medical personnel and the Aboriginal community expressed the need for increased access and availability of traditional treatment.

Chapter Five

Alternative Treatments

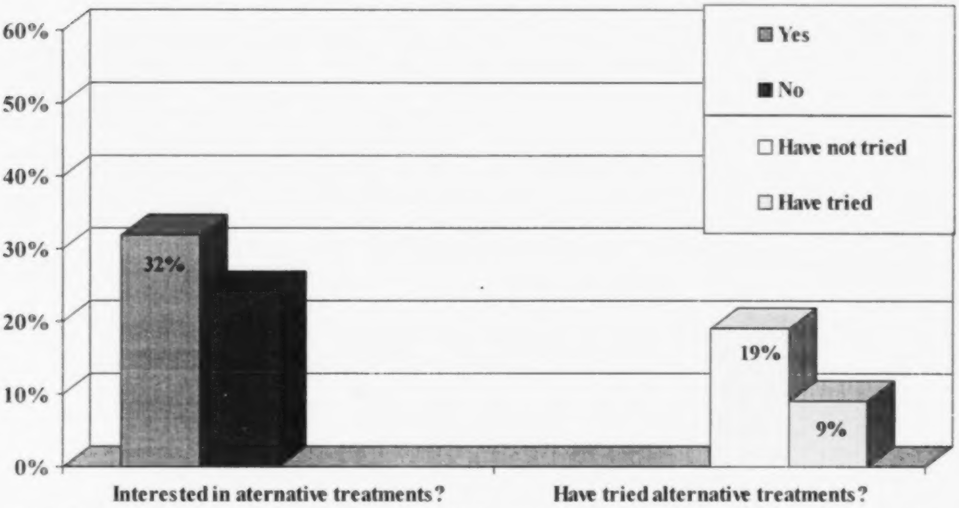
5.0 ALTERNATIVE TREATMENTS

5.1 Community Interviews

5.1.1 Interest in alternative treatments/medicines

Interviewees were asked, "Are you interested in alternative treatments?"

Figure 6: Interest in Alternative Treatment / Medicine



Note: Percentages may not sum 100 due to multiple responses and non-response. Base = 229 N = 131

32% (**74** respondents) **expressed an interest** in alternative treatments. Discussions about alternative treatments disclosed that many cancer patients and their families are willing to try anything that they think will help.

24% (**57** respondents) said that they were **not interested** in alternative treatments. In many communities, people are simply not aware of alternative treatments. Some expressed concerns about conflicts with prescription drugs. Participants were also asked whether cancer clients had tried alternative treatments.

19% (**44** respondents) **have not tried alternative treatments**. Some family members said they had tried to interest the cancer client, but had no success. Others felt that techniques such as meditation or prayer were safe but treatments such as medicines were risky. Still others thought they did not have any choice except what the doctors offered.

9% (**21** respondents) reported having **tried alternative treatments**. In most cases, cancer clients use alternative treatments for symptom control, mainly for pain.

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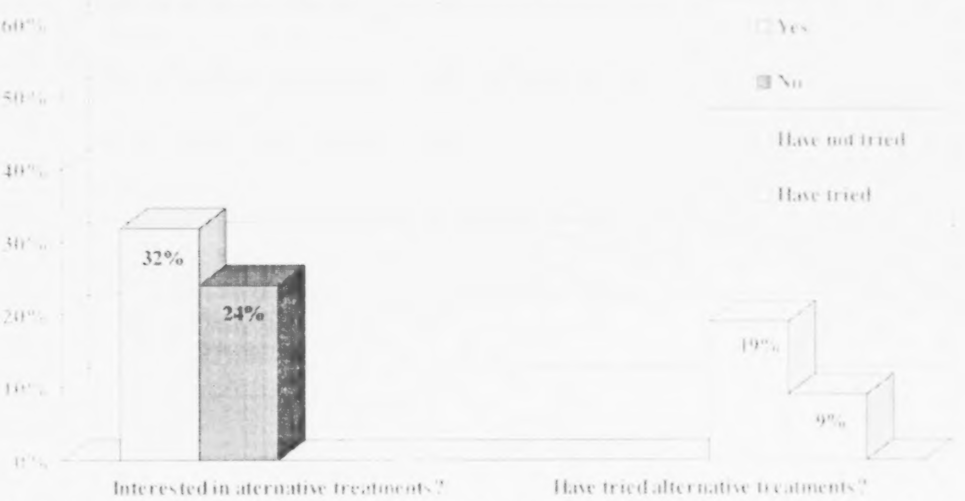

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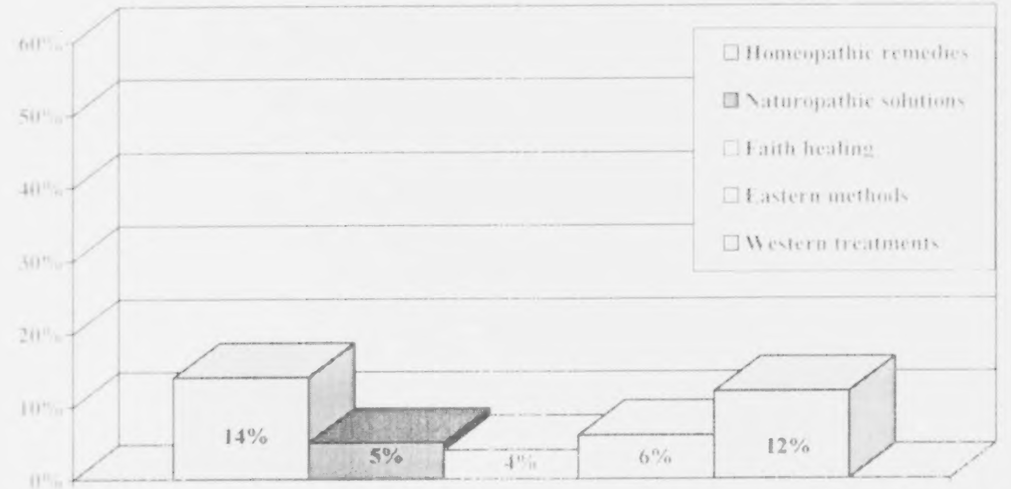
5.1.2 Types of alternative treatments

Respondents were asked what kinds of alternative treatments cancer clients had received.

Figure 7. Types of Alternative Treatments Used



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14% (**31** respondents) named a variety of **homeopathic remedies/herbal medicines**. Those specifically mentioned include: nettles, shark cartilage, sterol, essiac, green tea, slippery elm, aloe vera, chamomile and whiskey. Some of these products were said to be anti-oxidants, some were thought to build-up the immune system, and others to cleanse toxins from the body.

6% (**13** respondents) reported having used **Eastern methods of healing**, including acupuncture, reflexology, Tai Chi, yoga and/or meditation. Most frequently mentioned was acupuncture.

5% (**12** respondents) identified **naturopathic solutions**. Most cited changes in diet and the benefits of massage therapy to release stress from the body before it triggers the growth of cancer.

4% (**10** respondents) spoke of **faith healing, prayer, and spiritual intervention**. Most of the respondents in this group were talking about prayer in a Christian context.

12% (**27** respondents) answered the question about alternative treatments by naming the types of **Western medical treatments** cancer clients had received, including chemotherapy, radiation, and surgery (both laser and regular). It was apparent that these respondents considered traditional Aboriginal medicine as their primary source of treatment and

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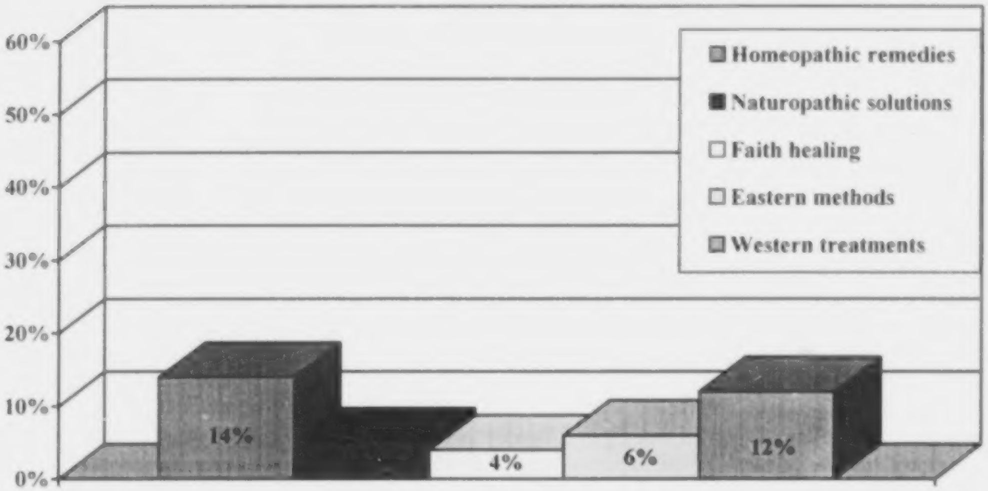

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Western medicine as an alternative.

5.2 Service Providers' Interviews

The service provider discussion groups were also asked for their thoughts on **alternative treatments for cancer.** Discussions were limited, however many providers expressed a willingness to remain open-minded. A few respondents stated that people should be able to make their own choices for treatment. However, they felt that not all conventional practitioners would be open to alternative treatments. One group reported that they had access to more information on alternative healing than on Aboriginal healing. One participant suggested that teaching relaxation, calming music, and Aboriginal music would work for Aboriginal patients.

5.3 Summary of Findings

Community interviews revealed that while there was considerable interest in alternative treatment for cancer, awareness of what these treatments might be and how they would be used was lacking. Further, there was a general feeling that most of the alternative remedies that might be tried would not be available to people in rural and remote communities. Respondents who had tried alternative treatments had found them most useful for relieving pain.

Chapter Six

Prevention

"Education. Education equals prevention."

– Respondent, Community Interview

6.0 PREVENTION

6.1 Community Questionnaire

In the community survey, participants were asked about types of **cancer prevention activities** that have been undertaken by their communities in the last two years.

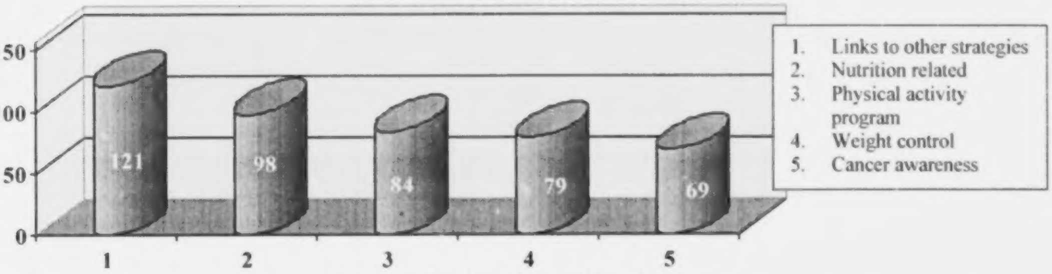

Figure 8: Cancer Prevention Activities in Communities

Note: numbers based on 157 participants

121 communities reported that links with other strategies such as diabetes and heart/stroke initiatives have been developed in their communities:

- **98** of these communities have links with diabetes programs or activities;
- **68** of these communities have links with heart and stroke prevention activities.

98 communities have carried out nutrition-related activities.

84 identified physical activity programs as their cancer prevention initiatives.

79 communities report that they have weight control activities.

69 communities say they have had cancer awareness sessions.

The activities tend to be one-time projects rather than ongoing. Other activities included breast screening clinics, prostate cancer awareness workshops, and smoking cessation initiatives. Promotion of traditional feasts, healthy lifestyles and awareness of alcohol and drug abuse were also identified as cancer prevention activities. Some communities noted that cancer awareness information was distributed through community newsletters and local radio shows.

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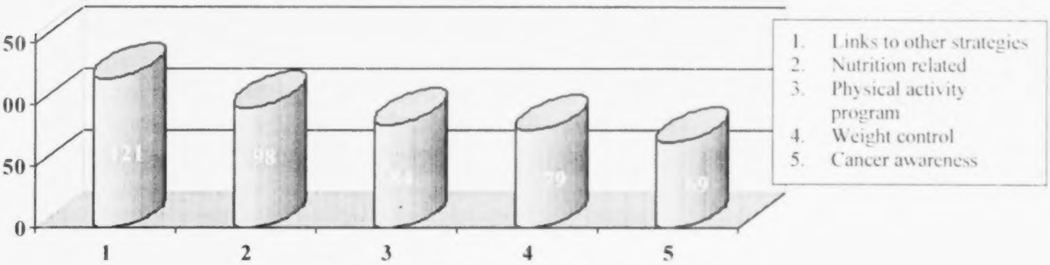

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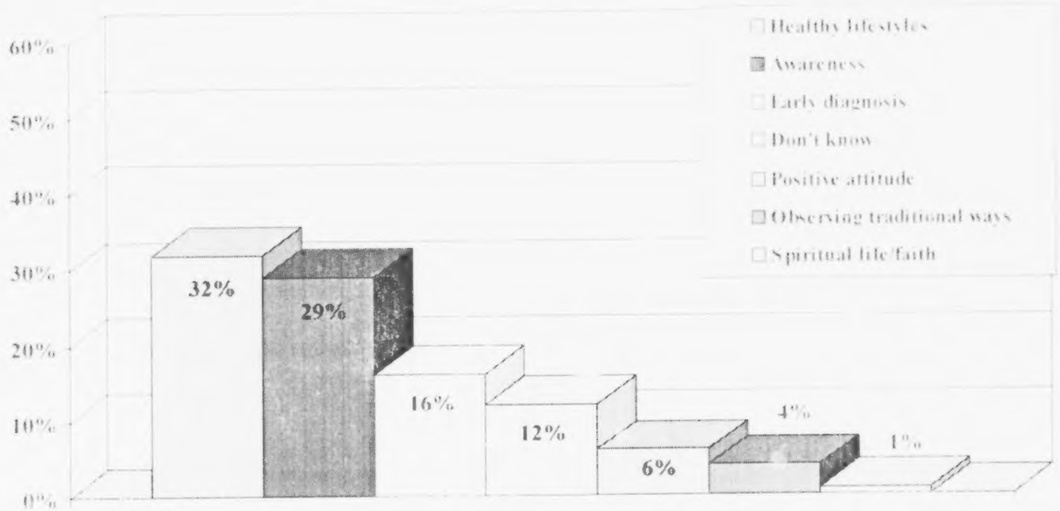
6.2 Community Interviews

Community study participants were asked the question, "What does 'prevention' mean to you?"

Figure 9: Interpretations of 'Prevention'



Note: Percentages may not sum 100 due to multiple responses and non-response. Base = 229   N = 230

32% (73 respondents) believed that cancer could be prevented, or at least the risks could be reduced through **healthy lifestyles.** The list of things to be avoided include (in descending order of frequency): smoking, fatty and highly processed foods, the sun, alcohol, hazardous environments, drugs, and sexually transmitted diseases. Lots of fruits and vegetables, exercise, spirituality/faith, rest and herbal supplements were seen as essential preventative lifestyle choices.

29% (66 respondents) of respondents thought the best route to prevention would be to **create awareness** of preventative measures **through education**. They felt that educating the public could reduce the risk of cancer. Communities need information about different types of cancer, what they need to do to prevent cancer, and what measures they should take to have a healthier lifestyle. It was felt that messages should start with children in elementary schools and be delivered in a culturally sensitive manner.

A number of health workers suggested that community organizations should be working together to get the message out to people.

16% (37 respondents) believed that the **best prevention is early diagnosis** and treatment, and stated that people should get regular check-ups before there is a problem.

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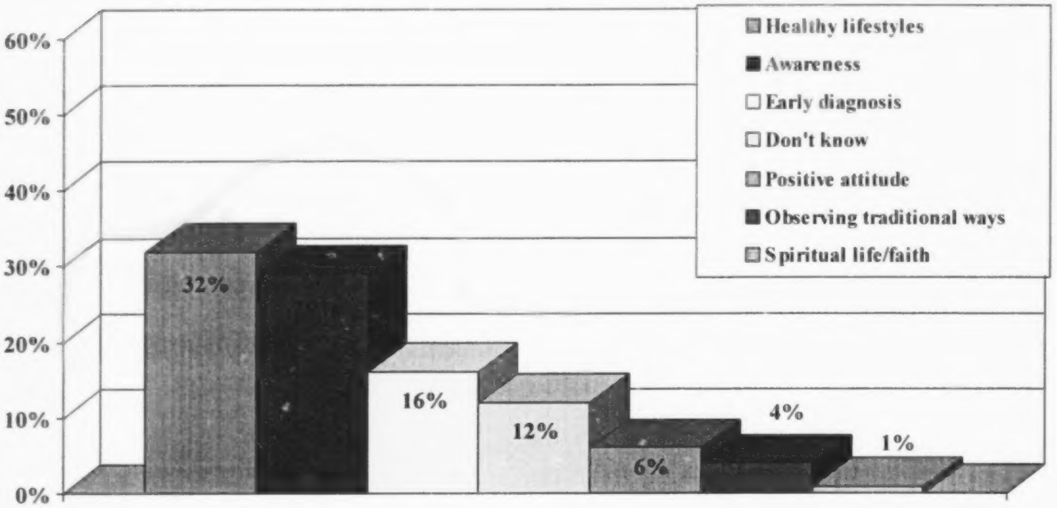

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32% (**73** respondents) believed that cancer could be prevented, or at least the risks could be reduced through **healthy lifestyles.** The list of things to be avoided include (in descending order of frequency): smoking, fatty and highly processed foods, the sun, alcohol, hazardous environments, drugs, and sexually transmitted diseases. Lots of fruits and vegetables, exercise, spirituality/faith, rest and herbal supplements were seen as essential preventative lifestyle choices.

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16% (**37** respondents) believed that the **best prevention is early diagnosis** and treatment, and stated that people should get regular check-ups before there is a problem.

12% (**28** respondents) said that they **did not know** what prevention means when it comes to cancer because they do not think cancer can be prevented.

6% (**13** respondents) thought the key to prevention was having a **positive attitude.** A number of people specifically mentioned the importance of dealing with unresolved feelings of anger and bitterness.

4% (**10** respondents) expressed that prevention meant **observing traditional ways.** These respondents expressed the idea that traditional foods are natural and healthy, and that traditional medicines prevent cancer.

1% (**3** respondents) said prevention means having **a faith and living a spiritual life.** The idea expressed was 'healthy spirit – healthy body'.

6.3 Service Providers' Questionnaire

Respondents were asked what **other programs their organizations provide related to cancer prevention specifically for Aboriginal people**. Five of the fifty responding service providers described the nutrition programs they offer, while four implement skin cancer prevention programs. Three organizations offer physical activity and active living programs, and three have programs specific to weight control. Two of the agencies do prevention work on high-risk behaviours, such as alcohol abuse, while one organization reported that it works on controlling exposure to environmental contaminants.

Individual programs developed by cancer service providers also include ones for diet and diabetes education, breast and cervical cancer prevention, and the promotion of heart health. One organization stated that their services are tailored to the general public, and are not specific to the Aboriginal community.

6.4 Service Providers' Interviews

Views on prevention were solicited among the cancer service providers. Among the discussion groups and interviews, participants strongly endorsed cancer prevention initiatives and the benefits they reap. They see the need to reduce the burden of cancer in Aboriginal people through early detection. The example most frequently given was that women are not checking their breasts regularly. Prompt attention to probe why First Nations patients are coming in with advanced disease needs to be addressed. Prevention is considered the first step in addressing the problem of late diagnosis.

6.4.1 More information

Service providers would like more specific information about certain types of cancer and incidence among Aboriginal people. They specified that information on how these cancers can be prevented and how screening can be promoted in Aboriginal communities is needed. Service providers would also like more information on the genetics behind cancer among Aboriginal people.

6.4.2 Prevention activities

Service providers would like to see the awareness of **family history** among Aboriginal people, raised so that people at greater risk can be encouraged to participate in prevention activities.

Participants made specific reference to **smoking and lung cancer**. Service providers in the discussion groups want prevention to concentrate on screening and education about smoking. They consider lung cancer to be preventable. Service providers also contributed thoughts on **smoking cessation.** The greatest emphasis was placed on prevention work among **children and youth**. Participants see large numbers of young people smoking, expressed particular concern for young girls, and felt that education is the avenue for getting the message across.

Members of two groups felt that messages about the effects of smoking need to be brought to communities so the "truth about tobacco" can be understood. They would like to see pamphlets and visual aids translated into Aboriginal languages, and prevention programs making use of local television and radio (Wawatay was cited as an example). That way, people of all ages get clear messages about smoking. They noted that generic messages about smoking are not being taken seriously.

One physician stressed that awareness among First Nations youth and adults is essential: *"Smoking is pleasurable and it is like alcohol and drugs. It has negative impacts on one's health. Smoking is an addiction, so this area definitely needs to be addressed."* This was the only mention that connected smoking cessation with addictions.

Service providers suggested prevention activities around alcohol abuse, tobacco with elders teachings, and promotion activities that encourage healthy lifestyles. One group suggested having an Aboriginal counsellor explain how prevention can save lives. They feel that programs need Aboriginal people to spread the information and create awareness, endorsing **education from within** by using role models, leadership, schools and nurses to deliver the message.

6.4.3 Outreach

A group from one of the larger urban centres expressed their concern that 40% of the homeless population was Aboriginal and that outreach support to them was needed. They would like to see prevention messages reaching out to all people.

6.4.4 Communication and education

In order to decrease cancer rates, it is important to get the information out through public education. Participants in the group offered suggestions about how that goal can be achieved, including the production of pamphlets and visual aids, in both English and the Aboriginal language. They pointed out the importance of involving influential Elders and community leaders in communication initiatives, and they would like to see more extensive use of the media, such as radio and television.

6.4.5 Diet and lifestyle

A different discussion group focused on the influential factors of diet and lifestyle. They highlighted that careful approaches to both areas are important in caring for one's body. They would like to see prevention campaigns aimed at making children aware of healthy dietary choices. They also felt a strategy is necessary to address the difficulty for isolated northern communities gaining access to fresh fruits and vegetables. One participant pointed out that changing behaviour is the biggest challenge. Prevention initiatives need to include the message that making changes, eating healthier foods and getting exercise in daily lifestyle, can prevent cancer.

Diet and lifestyle were also the focal point of discussions on prevention among traditional healers. They feel strongly that cancer comes from the transition from traditional Aboriginal to a more contemporary diet and lifestyle.

From a physician's point of view, early detection is key, particularly in the area of colon cancer. It was pointed out that because Aboriginal patients tend not to complain much, they do not report symptoms early enough. Education on prevention would inform people about possible symptoms, so they might seek medical services earlier.

6.5 Secondary Research

A number of videos have been developed to create awareness about cancer prevention among Aboriginal people. Currently, the First Nations and Inuit Health Branch has categorized prevention as a theme in their inventory of cancer care activities and programs for Aboriginal people (2000). Other inventories on prevention initiatives include works by Michalek and Mahoney (1994); the OCTRF (1996); a cancer control program for the Sioux Lookout area (Northwestern Ontario Cancer Centre, 1997); and the Northern Ontario Cancer Profile Report (Cancer Care Ontario, 2000).

Many articles discuss prevention and/or difficulties in reaching Aboriginal people for screening. They often look at factors common to Aboriginal cultures in efforts to identify barriers to participation in screening (Opie and Hakenberg (undated); Cooper, et al., 1991; Birdsell, et al., 1992; Brownstein, et al., 1992; Deschamps, et al., 1992; Wilcox and Mosher, 1993; Sugarman, et al., 1994; Burhansstipanov, 1998; and the First Nations and Inuit Regional Health Survey report, 1999).

Some of the issues and variables explored by the articles include health practices and beliefs, lack of awareness, beliefs about communication, orientation, family relationships, education, religion, social and ethnic barriers, first language or dialect, geographic access to clinics, and lack of Aboriginal culture in the recruitment literature.

Several analyses of **screening programs or projects** have been conducted (OBSP, 1992; Calam, et al. 1992; Hislop and Band, undated). Regional American programs and projects reviewed include Brownstein, et al. (1992) on breast and cervical screening in Arizona; Welty (1992) on cervical and breast screening and causes and rates for specific cancer types in the Aberdeen Area of the northern plains (US); Weiner (1993) on the influence that California's Luiseno Indian beliefs about cancer causes have on prevention; Schanche Hodge, et al. (1995 and 1998) on smoking prevalence and culturally appropriate cervical breast cancer education in Northern California Indians; Dignan, et al. (1995/96) on cervical cancer education among the Eastern Cherokee, and Native American women in North Carolina; Stillwater, et al. (1995) on a cervical cancer prevention video for Alaska Native women; Strickland, et al. (1996) on Pap screening among the Yakama; Olsen, et al. (1996) on cervical cancer screening in California; Stovall and Wright (1998) on reaching Native American women in Texas for breast cancer screening; Becker, et al. (1999) on cervical screening in New Mexico; and Brant, et al. (1999) on breast health for Plains Indian women in the United States.

National American programs reviewed were Burhansstipanov (1993) on intervention projects conducted by the National Cancer Institute, and Schinke, et al. (1994) on a software program to improve dietary choices and prevent tobacco use among Aboriginal youth. The difficulties and learning experiences encountered supplement these positive reviews.

Articles on either incidence or risk that make recommendations for preventive programs include works by Young and Choi, (1985); Lanier, et al., 1989; Freitag, et al., (1990); Gaudette, et al., (1990) and (1993); Gillis, et al., (1990); Irvine, et al., (1990); Hampton, (1992); Nutting, et al., (1993); Sugarman, et al., (1994); Thiemann, (1994); Davis, et al., (1995); Gilliland, et al., (1998); Kottke and Trapp, (1998); Marrett, (1998); Harvald, (1990); and the Gane Yohs Community Health Centre, (2000). They discuss elevated rates for certain site-specific cancers or concern over survival when diagnosis occurs in later stages.

6.6 Summary of Findings

Many Aboriginal participants acknowledge that prevention activities such as healthy lifestyle choices and early detection can reduce the risks of cancer. The best way to prevent cancer is to create awareness of prevention measures through public education. Other prevention methods include early diagnosis and treatment; positive attitude; observing traditional ways; and spiritual life and faith.

However, while early detection and treatment are seen as critical factors in prevention and survival, anecdotal evidence suggests that many Aboriginal people are not diagnosed until later stages of the disease. Aboriginal people routinely have a lower participation rate in early detection activities such as screening programs.

Education and awareness campaigns and efforts to encourage healthier lifestyles, including smoking cessation, are a priority for both community members and service providers. In addition, efforts are needed to increase Aboriginal participation in screening programs. A number of health workers recommended that community organizations should work together to get the message out to the communities.

Only only a few service providers offer cancer prevention programs specifically for Aboriginal people. However, health workers strongly endorsed cancer prevention initiatives and believe in the benefit of prevention activities. They would like to see more culturally sensitive education promoting prevention and early detection activities, which include self-exams and regular screening. They suggested making pamphlets, in both English and

Aboriginal languages, and wider use of the media, especially television. They pointed out that it is important for influential elders and community leaders to help communicate appropriate messages.

Chapter Seven

Use of Tobacco

"The current no-smoking campaigns are not enough. In fact, the pictures on cigarette packs are being collected by the kids like hockey cards."

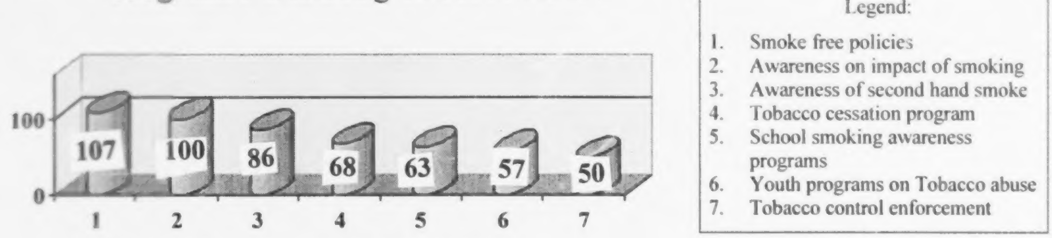
- Respondent, Community Interview

7.0 USE OF TOBACCO

7.1 Community Questionnaire

In the community survey, participants were asked what type of **community programs or activities** have been undertaken regarding the use of tobacco in their communities.

Figure 10: Number of Community Programs Addressing Tobacco Abuse



Note: numbers based on 157 participants

107 out of 157 communities **(68%)** reported that they have smoke-free policies in their communities.

100 communities **(64%)** have worked on awareness on the impacts of smoking.

86 (55%) report that they have focused on awareness of the impacts of second-hand smoke.

68 (43%) communities have set up tobacco cessation programs.

63 (40%) have implemented school programs on smoking and its effects.

57 (36%) communities have set up youth programs related to tobacco abuse.

50 (32%) communities reported that enforcement of tobacco-control regulations has been emphasized.

It should be noted that while relatively high percentages of communities currently have tobacco related programs, many of the programs are short-term and/or one-time programs.

Other programs or activities include youth courses on tobacco abuse and utilization of youth mentors on healthy living. Health fairs and school programs were also identified as important programs initiated at the local level. Awareness sessions were seen as essential in the communities as well as recognition of those individuals who have chosen healthy lifestyles.

In the community survey, 85 out of 157 communities (54%) report that they provide **teaching on the traditional use of tobacco**.

Participants were asked in what ways the teachings are delivered. The most common methods are through workshops, school programs, traditional ceremonies and sharing circles. It was also noted that information on traditional use of tobacco is distributed through newsletters, posters and pamphlets. Community members emphasized the importance of including elders and traditional people in tobacco use initiatives.

7.2 Community Interviews

7.2.1 The risks of non-traditional use of tobacco

Participants were asked, "Should people be made aware of the risks of non-traditional use of tobacco?".

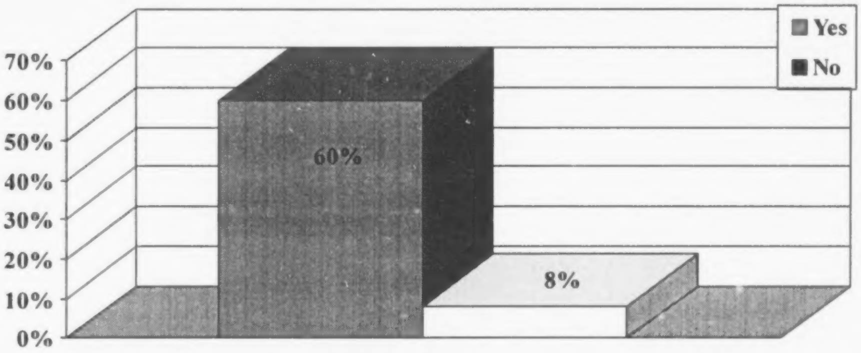


Figure 11: Should People Be Made Aware of the Risks of Smoking?

Note: Percentages may not sum 100 due to multiple responses and non-response. Base = 229 N = 157

60% (**138** respondents) felt that people should be aware of the risks of the non-traditional use of tobacco. Seventy-two people did not answer this question.

Of those who replied, the vast majority strongly agreed that Aboriginal people should be made aware of the risks of non-traditional uses of tobacco. About half of these respondents expanded on their answers. A number commented that there is already a lot of publicity on the health hazards associated with smoking, and they questioned its effectiveness, pointing out that for youth it might actually promote smoking for the thrill. Campaigns should begin with very young children, because they start experimenting with smoking at an early age.

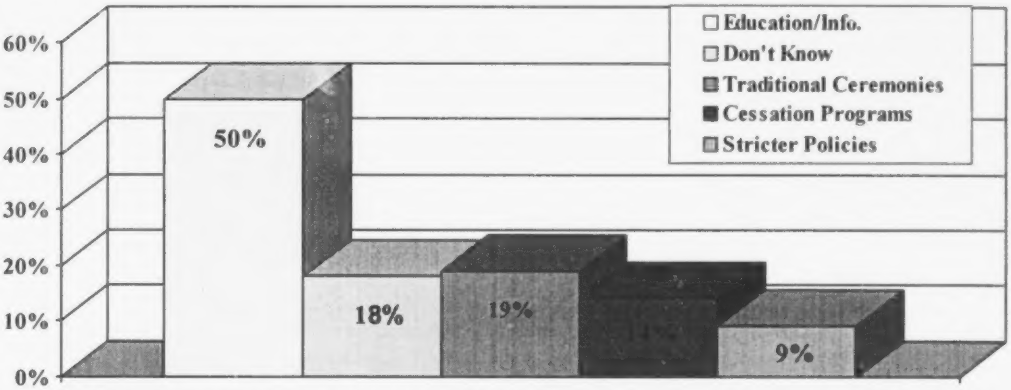
Several respondents commented on the fact that there is not enough knowledge about the value of traditional uses of tobacco and the risk of the chemicals in commercial tobacco.

8% (**19** respondents) said it is not important for people to be made aware of the risks. Most respondents expressed the opinion that the message about the hazards of smoking has already been widely publicized, and everybody already knows. Some said they found the current anti-smoking initiatives offensive. Some stated that they do not believe that smoking causes cancer.

7.2.2 How can awareness be created regarding traditional vs. non-traditional tobacco uses?

Participants were asked to suggest ways in which the awareness of the dangers of tobacco abuse and the difference between traditional use of tobacco could be increased.

Figure 12: Methods of Creating Awareness



Note: Percentages may not sum 100 due to multiple responses and non-response. Base = 229 **N = 251**

50% (**115** respondents) felt the best way to create awareness is through providing **education/information.** The majority of people felt there needed to be more effective education on both the traditional and non-traditional uses of tobacco. Many participants indicated that people in the Aboriginal community need to be better informed about the traditional and/or sacred uses of tobacco, and that the message should come from the elders and healers who are knowledgeable in this area. In terms of non-traditional uses of tobacco, respondents recommended that the risks of smoking and its links with cancer be outlined clearly and graphically through illustrated information sessions. There was general agreement that sessions should be given in schools, to reach children, the younger the better. Others said the same information should be delivered to pregnant women and new parents.

18% (**42** respondents) said they **did not know** what could be done. Despite a strong message, smokers continue to ignore the risks.

19% (**43** respondents) felt awareness of traditional uses could best be created through participation in **traditional ceremonies.** Respondents in this group observed a need to teach the proper use of tobacco in traditional ceremonies, with a focus on distinguishing it from non-traditional abuses. A significant number noted that children should be taught from an early age. More than one respondent heard of traditional ceremonies being featured in day care centres to teach children the spiritual use of tobacco. Several observed that the traditional use of tobacco is used to take prayers up to the Creator; therefore, as a

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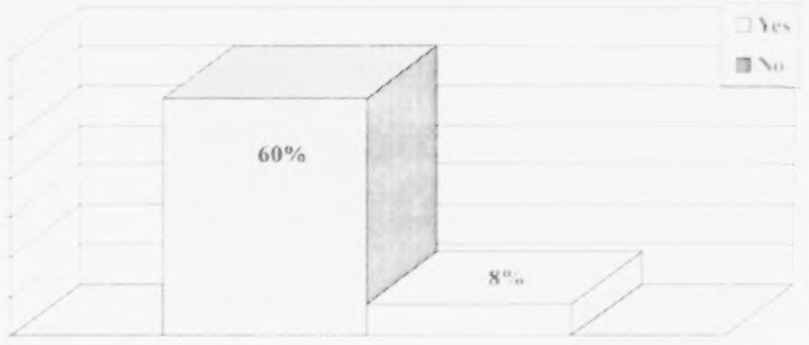

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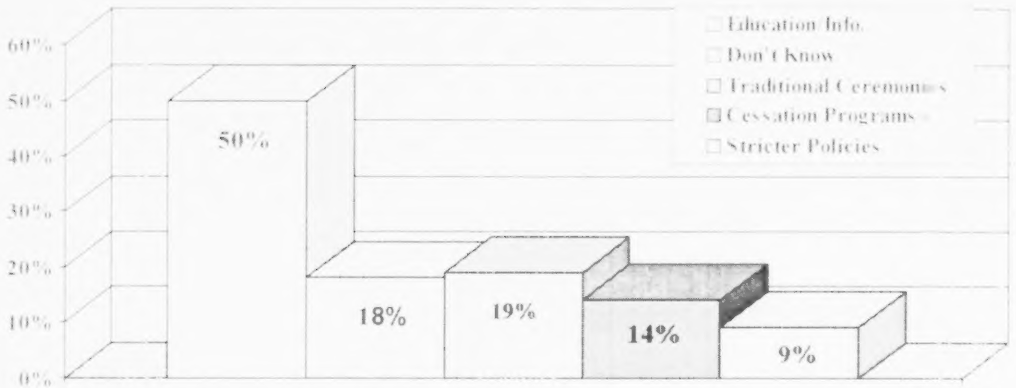

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50% (115 respondents) felt the best way to create awareness is through providing **education/information.** The majority of people felt there needed to be more effective education on both the traditional and non-traditional uses of tobacco. Many participants indicated that people in the Aboriginal community need to be better informed about the traditional and/or sacred uses of tobacco, and that the message should come from the elders and healers who are knowledgeable in this area. In terms of non-traditional uses of tobacco, respondents recommended that the risks of smoking and its links with cancer be outlined clearly and graphically through illustrated information sessions. There was general agreement that sessions should be given in schools, to reach children, the younger the better. Others said the same information should be delivered to pregnant women and new parents.

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14% (31 respondents) requested more/better **smoking cessation programs to help people quit.** People in this group expressed the view that tobacco, especially the chemically laced variety found in cigarettes, is highly addictive. Smokers need more help to enable them to quit. A number of health workers described cessation programs that offered incentives. Generally, those who had participated in current smoking cessation programs found them effective. However, several people observed that cessation programs in Aboriginal communities should be culturally based, and while helping participants quit smoking, should also include teaching about the traditional use of tobacco to avoid confusion. A significant number of people also identified the need for cessation programs geared towards youth, while prevention programs should be geared towards younger children.

9% (20 respondents) called for **more stringent policies** concerning both the traditional and non-traditional uses of tobacco. Many in this group wanted to see more stringent enforcement of the rules aimed at preventing minors from obtaining cigarettes, and stricter enforcement of policies regarding second hand smoke. Some commented that they still see pregnant women and parents of small children smoking. One was concerned about smoking during pregnancy and the lack of support for smokers who quit and then start again when under stress. Others complained that restaurants in Aboriginal communities still permit smoking.

Several people expressed concerns about the traditional uses of tobacco as well. Some did not like the fact that commercial cigarette tobacco was being used in traditional tobacco ceremonies. Others complained that smoke from smudges was being imposed upon them without their permission.

7.3 Service Providers' Questionnaire

The service providers described **tobacco-related programs for use in Aboriginal communities.** Of the 50 responding agencies, 11 said they have community awareness programs. Four said they have developed capacity-building training and consultation programs. In the area of **prevention**, seven have implemented programs for schools and two offer programs for parents or families. Seven indicated that they offer youth-specific programs and four present restrictions to youth access for tobacco.

Three of the service agencies have programs to increase awareness of Aboriginal cultural practices regarding **traditional tobacco use**. One organization responded that they have tobacco-related programs specific to Aboriginal people.

Smoking cessation programs are offered by seven of the responding service agencies. In addition, one agency indicated that they have a smoking cessation program in place in a First Nations community school. Another described a smoking cessation program offered to the general public, but indicated that it is not specific to Aboriginal people.

7.4 Secondary Research

7.4.1 Health effects of non-traditional use of tobacco

There are conflicting data on the incidence and mortality rates of lung cancer in Aboriginal populations. Canadian studies suggesting the higher rates of lung cancer in Aboriginal people include: Marrett, (1998); Robinson, (1990); Irvine, et al., (1990); Frietag, et al., (1990); Gaudette, et al. (1990); and Hildes and Schaefer, (1984). There are similar data in the USA (Samet, et al., 1987; Lanier, 1989 and 1998; Mahoney, et al., 1989; Welty, et al., 1993; Hampton, 1992; Baquet, 1996; Burhansstipanov, 1998). In contrast, some research suggests a lower incidence of lung cancer among Aboriginal people, (Young and Frank, 1983; Mahoney and Michalek, 1991; Baquet, 1996), and a lower mortality rate (Mao, et al., 1992; Cobb & Paisano, 1988; Michalek, et al., 1989).

Data collected by Cancer Care Ontario clearly shows that the rate of lung cancer is increasing, both as a percentage of Aboriginal population, and in comparison to the general population (Marrett, 2002, unpublished). Smoking has risen in Aboriginal communities and studies show a dramatically high use of tobacco (Hart Hansen, 1009; Harvald, 1990). There is widespread concern about smoking among youth and young children and there are studies showing very high rates of smoking (Pickering, et al.; Davis, et al., 1995).

7.4.2 Ways to create awareness on the traditional and non-traditional use of tobacco

The literature identified a gap in information about tobacco as a sacred plant and its use by traditional healers in ceremonies (Welty, 1992). However, some literature identified the difference between ceremonial and recreational tobacco use (Mahoney and Michalek, 1999).

Programs are beginning to promote smoking cessation using posters, brochures, and literature that reflect Aboriginal culture. Workshops, public forums and some activities described in the prevention section are beginning to associate the dangers of tobacco abuse at the community level. Positive messages delivered by elders and cancer survivors are proving to be effective. Examples of finding creative ways to reach the youth can be found in the software program described by Schinke, et al. (1994), or in providing situations where community people from various ages and backgrounds enter into discussions using talking circles. Aiming to create an attractive, effective means of reducing cancer risks faced by Native Americans (Schinke, et al., 1994), some research has shown that interactive computer software on dietary and tobacco choices holds promise for delivering cancer risk reduction and intervention for Native American youth.

7.5 Summary of Findings

The community survey found a high rate of communities (greater than 50%) that have smoke free policies, and have worked on awareness for smoking and second hand smoke. Smoking cessation and school programs were reported by more than 40% of communities, and more than 30% have tobacco abuse programs for youth and enforcement of tobacco control regulations. It is recommended that the results be viewed cautiously as many programs may be one time only presentations or short-term initiatives and may not represent a long term initiative.

In terms of the ceremonial use of tobacco, the community questionnaire found that 54% report having offered teachings on the traditional use of tobacco, and the importance of elders.

Results of the community interviews revealed that 60% felt that people should be made aware of the risk of smoking, and added that there is already a lot of information available. It was noted that, in particular, children and youth need effective programming.

The results of the community interviews on traditional (sacred or ceremonial) and non-traditional (commercial tobacco products) use of tobacco showed that education and information were cited (50%) as most effective, followed by participation in traditional ceremonies, cessation programs and stricter polices.

Service provider questionnaires revealed a low response rate for tobacco related programs for use in Aboriginal communities. Research shows a high and growing rate of smoking, especially among Aboriginal children and youth. Lung cancer is one of the most frequently occurring cancers among Aboriginal people, and the incident rate is increasing. Some research examined the use of interactive computer programs to engage youth.

Communities are concerned about the impact of smoking, and they want more information and smoking cessation programs. They would also like support in developing and enforcing policies about smoking in Aboriginal community facilities. In order to be effective, these programs need to be designed to be culturally relevant, linguistically accessible and include reference to the traditional uses of tobacco.

Chapter Eight

Cultural Sensitivity of Cancer Services

"There is a great need to make hospitals and medical people aware of special needs in communities, traditional practices, and ceremonies, so that they can be integrated into their institutions."

– Traditional Healer

8.0 CULTURAL SENSITIVITY OF CANCER SERVICES

8.1 Community Interviews

Study participants were asked three questions to examine the cultural sensitivity of cancer services:

- Are cancer services culturally sensitive?
- Should cancer services be culturally sensitive?
- How could cancer services be made more culturally sensitive?

8.1.1 Are cancer services culturally sensitive?

34% (79 respondents) said currently cancer services are not culturally sensitive. The opinion of this group of people was that most cancer services treat the disease, not the patients, contrary to the holistic view of health that most Aboriginal people hold. They felt that while local services may provide somewhat more culturally appropriate services for Aboriginal people, services in larger urban centres do not. Issues of short time periods with the physician, lack of access to traditional healers, and insensitivity of health care workers were noted.

31% (72) said cancer services are culturally sensitive. Of the 190 participants that responded to this question, 38% said **yes**, cancer services are culturally sensitive. There was general agreement that cancer services as a whole are becoming more culturally sensitive. Responses revealed that there are pockets of cancer care service providers throughout the province who try very hard to understand and accommodate the particular needs of Aboriginal patients and their families. In these areas, medical staff recognize the importance of traditional ceremonies such as prayers and smudging, accommodate larger numbers of family members in hospital rooms, and make cancer patients and their families feel comfortable.

Respondents identified accommodation for **large extended family groups** and **traditional ceremonies** as examples of efforts to provide culturally appropriate care.

Language was identified as an important component of cultural sensitivity, including the importance of providing interpreters. A number of people commented that one of the greatest factors in the increased cultural sensitivity is the presence of **Aboriginal medical staff**.

17% (**39** respondents) said that they **did not know** whether or not cancer services are culturally sensitive. The majority of these respondents did not understand the question. Others declined to comment because they felt they did not have enough knowledge of cancer services. Several believed that it depends on the community, stating situations vary from location to location.

Differences in opinion were found to exist among the types of respondents regarding the cultural sensitivity of current cancer services. The table below shows that 48 percent of cancer clients say cancer services are **not culturally sensitive** compared with only 20 percent of health workers, and 34% of family members.

8.1.2 Should cancer services be culturally sensitive?

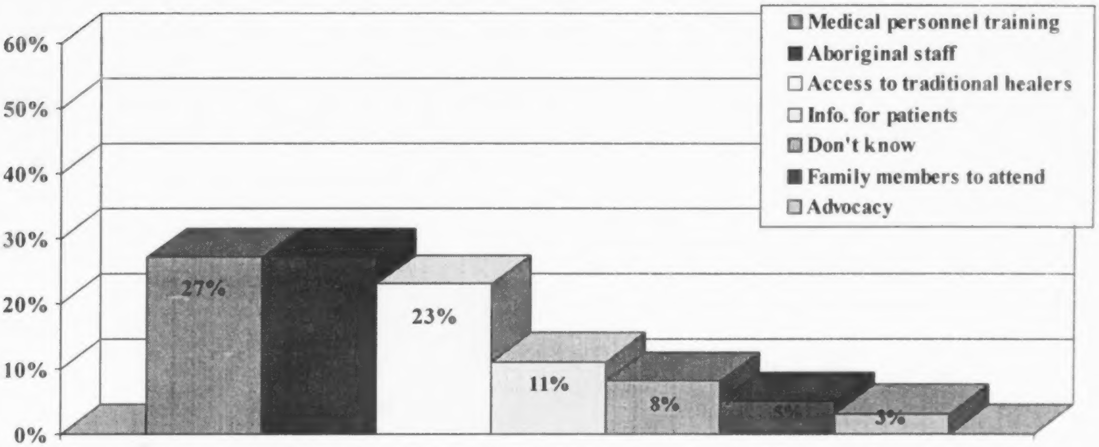
49% (**112** respondents) said that cancer services **should be** culturally sensitive. Most people in this group responded to the question with a simple, "yes" or "definitely". Some thought cancer services should be sensitive to peoples of all cultures. Others commented that the choice should be available to cancer clients and their families.

5% (**11** respondents) said they **did not believe** cancer services should be culturally sensitive. Most respondents in this group did not want to see Aboriginal clients singled out for special treatment. They felt that cancer services should be sensitive to all cancer patients, and that everyone should be treated equally.

3% (**8** respondents) said they **did not know** if cancer services should, or could, be made culturally sensitive.

8.1.3 Suggestions for making cancer services more culturally appropriate

Figure 13: Ways To Improve the Cultural Sensitivity of Cancer Services



Note: Percentages may not sum 100 due to multiple responses and non-response. Base = 229 N = 237

27% (**61** respondents) recommended **cultural sensitivity training for medical personnel**. Respondents called for the whole health care team (oncologists, physicians, nurses, social workers, dieticians, translators, etc.) to be educated about how the Aboriginal worldview comes into play in the provision of cancer services. There was also a fair amount of support for cultural sensitivity workshop training to be delivered by Aboriginal health workers or by Aboriginal experts on cultural knowledge.

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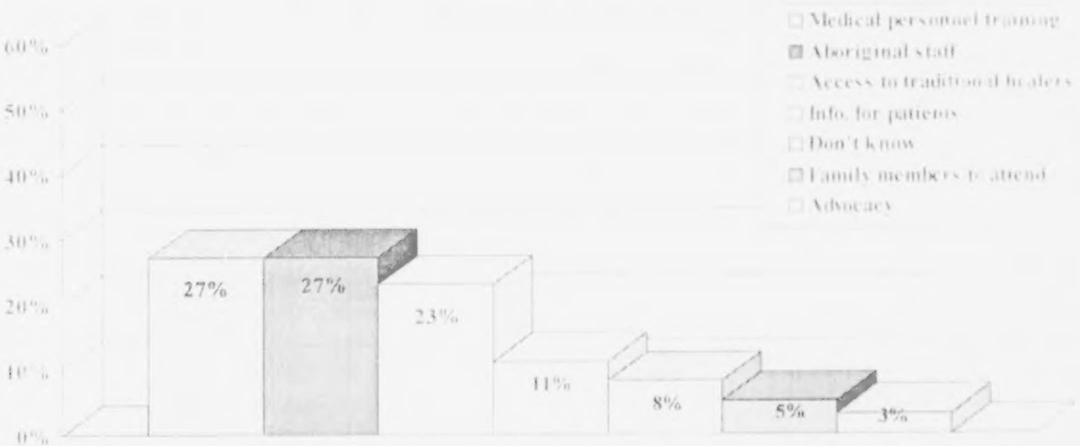

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27% (61 respondents) recommended the inclusion of more **Aboriginal staff** at cancer service facilities. The vast majority of those were recommending an Aboriginal "cultural interpreter" or liaison workers to serve as a guide, a companion and an advocate to "come along side" of Aboriginal cancer patients to guide them through the maze of cancer care options. This liaison person would have knowledge not only in the Aboriginal ways but also on the Western treatments to help people make informed decisions. The ideal person for this job as described by respondents would:

- be an Aboriginal person who understands and believes in Aboriginal culture, values and practices;
- have a comprehensive knowledge of the service and entitlements of Aboriginal patients;
- be able to access the expertise and the knowledge of Aboriginal professionals in the community (including traditional healers that specialize in cancer care);
- provide language translation/ interpretation in difficult medical situations; and
- provide comprehensive palliative care service for Aboriginal people.

23% (52 respondents) recommended **access to traditional healers**. They feel that Aboriginal cancer patients and their families should have the option of choosing or including traditional healing in their cancer care. One obstacle to this choice is that Aboriginal clients do not know where to find traditional healers, and particularly those who specialize in treating cancer.

11% (25 respondents) requested **information for patients** that is culturally appropriate. Both cancer patients and their families have a spectrum of information needs. Oncologists may not clearly communicate the circumstances of the disease or have enough time to explain. Language barriers further complicate the communication process. Terms and translation are not standardized and there are many dialects. A number of respondents mentioned that they needed information about where cancer services were available within their communities. Others wanted information about how to find and retain the services of traditional healers.

Some respondents recommended that information packages (in appropriate languages) be made available within each community. Types of information that they thought should be included are:

- what cancer treatment involves, and what to expect;
- an up-to-date comprehensive listing of the services that are available to cancer patients and their families in each community;
- updates on medications used in cancer care;
- a list of traditional healers that specialize in cancer care; and
- what is involved in caring for a cancer patient and the provision of palliative care.

8% (19 respondents) said they **did not know** how cancer services could be made more culturally sensitive.

5% (12 respondents) said cancer services could be made more culturally sensitive by **allowing family members to visit** or accompany cancer patients to the medical centres. These respondents made the point that it is particularly important for Aboriginal people to have the family together at important times, especially when a family member is dying. What is needed from cancer service providers is both understanding for the cancer patient and family members, and space to accommodate them. Service providers need to understand that family means extended family to many Aboriginal people, and that an Aboriginal cancer patient may want a large number of these extended family members with them.

3% (7 respondents) noted that some Aboriginal people do not speak up for themselves, and recommended **advocacy**. Some spoke of needing advocates for cancer patients and their families, who often do not know their rights or do not speak up. Others felt health workers should be advocating with cancer care providers to raise awareness on cultural issues and help them understand how cancer services can be made more culturally sensitive.

8.2 Service Providers' Questionnaire

The service providers were asked to describe any **culturally relevant materials on cancer** that they have developed for use in Aboriginal communities. The majority (80%) stated that **no specific materials had been developed**. Only three of the programs have pamphlets specific to Aboriginal people. Two agencies have produced videotapes; one described a poster, and one developed a presentation. Some agencies also pointed out that they use materials from other organizations such Health Canada, the Manitoba Cancer Foundation, and Aboriginal organizations. No newsletters or school materials specific to cancer among Aboriginal people were reported.

Ten agencies (20%) described **plans to deliver Aboriginal-specific programs within the next 12 months**, including:

- offering an educational session on the ACCU for their staff;
- hosting a community clinic on the nearby reserve;
- scheduling smoke free policy discussions;
- delivering screening to one First Nation community;
- conducting health fairs;
- distributing health promotion materials specific to Aboriginal women (i.e. cervical screening);
- holding a women's wellness day;
- using a First Nations video on breast health; and
- hosting a breast screening day.

8.3 Service Providers' Interviews

In their discussions on **cultural appropriateness of services,** service providers talked about the need to:

- build a better understanding of Aboriginal culture, the people and the issues they encounter;
- establish trust among Aboriginal clients;
- foster respect for holistic approaches to healing, if patients choose traditional healing;
- improve communication between their facilities and the Aboriginal clients they serve;
- take a closer look at their own services including instances where exceptions have been made to facilitate Aboriginal cultural wishes; and
- investigate supportive care, after care and palliative care needs for Aboriginal people from a cultural perspective.

8.3.1 Cultural awareness and the need for more information

Service providers see the need to have access to more cultural information about Aboriginal people as it pertains to cancer care. They see the need to improve access to traditional healing. They would like to learn more about traditional approaches to healing, particularly in the areas of pain and symptom management, which will help improve their ability to serve as a resource in this area. Some have already sought this information because they encounter Aboriginal patients who have difficulty talking about side effects, toxicity, and the feelings they experience during treatment. Some Aboriginal patients may be reluctant to discuss their traditional treatments. One physician stated hope for improvements in sensitivity for palliative and supportive care for Aboriginal people. Orientation videos were suggested to help Aboriginal cancer patients.

Some communication problems stem from the fact that service providers lack an understanding of the personal and social issues in an Aboriginal patient's background. Participants note that, aside from their medical needs, many Aboriginal clients harbour negative feelings about the disease or their care situation, and it impairs their communication with treatment providers. Some feel pressured and overwhelmed by the rapid changes taking place and they need more time to accept their situation, consider treatments, and rationalize the implications. Isolation from their home environment is also a great factor in communication breakdown.

Some respondents would like to see a combination of traditional and modern medicine, which fosters a blending of attitudes between the two cultural approaches in order to improve overall conditions.

8.3.2 Establishing trust

Group members discussed the challenge of establishing trust with Aboriginal clients. They felt that ACCU coordinators serve as important links with communities, and would like to see the JOACC *Code of Ethics* used by all people providing cancer services to Aboriginal people. (See the Code of Ethics in Appendix B).

8.3.3 Communication challenges

Service providers need a greater understanding of the socio-economic conditions of Aboriginal people in order to improve communications. Service providers identified a need for interpreters for Aboriginal language speakers and for people who need simple explanations of complex medical terminology and procedures. At the moment, patients and their families are dealing with communication barriers, and they feel that interpreters would help. One physician pointed to the importance of having Aboriginal people who know the language involved in providing care. Print materials geared to Aboriginal audiences were suggested, as was the need for patients to have time to reflect on their health situation and to prepare for their care.

Concerned with networking, one cancer service provider sees the need to undertake outreach services to the communities rather than always expecting community members to come to the medical centres. Also suggested was a tele-health system, with an oncologist at the Regional Cancer Centre. They would need to form a partnership with the federal government in setting up a network system into the north.

8.3.4 Service delivery issues

One agency reported that work to connect people and help them access culturally appropriate services was being done on an individual basis but was not a part of their policy. They explained that staff may lack the ability and desire to offer extra assistance. Another group talked about high staff turnover as a problem, and a third was unsure if they even had Aboriginal clients. Recognizing the inequities among communities, one of the service provider groups mentioned they would like to have Aboriginal staff at the CCORs in order to build on their understanding of the culture.

Among the Aboriginal-specific services that service providers would like to see is a public forum on education and screening to establish prevention networks and early detection. This is viewed as a more positive beginning. One physician suggested that campaigns to promote pap testing, mammograms and other kinds of testing would be more successful if these campaigns ran through networks and media that reflect Aboriginal culture. One of the groups suggested that half-day screening and sensitivity training sessions on breast screening be done through social events for women.

One regional cancer centre would like to have advocacy staff available to assist with supportive care. They see the need to work more closely with people who provide outreach services and to hire more Aboriginal staff.

8.3.5 Palliative and after care

One physician commented that little has been done to address specific Aboriginal issues, particularly in the area of palliative care and comfort. Again, the need for a navigator in cancer clinics and hospitals to ease anxiety and provide explanations was expressed by one of the service provider discussion groups. Supportive care, aftercare and palliative care are areas in which medical people need to be culturally sensitised so that they are aware of community practices, ceremonies and the Aboriginal world view.

8.3.6 Identifying Aboriginal cultural needs

Only one of the cancer service providers reported that they have few or no Aboriginal clients. They added that it may be hard to identify who Aboriginal clients are because they do not declare their ancestry in the intake process. A suggestion was made to build into the clients' chart specific questions about their needs in order to help identify the services required.

8.4 Secondary Research

Research (primarily in the United States) supports the need for, and effectiveness of, culturally specific cancer prevention initiatives. It supports the concern that general cancer prevention messages are not getting through to Aboriginal people. The following cultural issues were revealed in the literature:

- Aboriginal women participate less in screening programs (Hislop, et al., 1992 and 1996; Calam, et al., 1992);
- Culturally appropriate prevention programs improve participation (Welty, 1992);
- Aboriginal women have higher rates of mammography appointment failures (Margolis, et al.);
- Advocacy activities for Native Americans, and culturally specific intervention are justified (Baquet, 1996);
- Outreach to Aboriginal people required service providers experienced in working with these populations (Stovall and Wright, 1998; Hampton and Maher, 1998);
- Isolation from the home community creates care issues (Harvald, 1990);
- Language barriers (Harvald, 1990, Birdsell, et al., 1992).

Some best practices described in the literature include:

- Low-literacy breast cancer education materials and training to sensitize nursing professionals on how to build trust and better understand the Aboriginal culture were used to address the finding that low-education and fear of cancer contributed to the poor five year survival rate of Native American women (Brant, 1999);
- Many projects developed to reach Aboriginal people approach cancer care by demonstrating cultural sensitivity. They promote holistic care for the entire being, including the mental, spiritual and emotional experiences that accompany the physiological changes a cancer patient (or potential patient) will encounter. Adjustment to include cultural content is aimed at supplementing traditional western approaches to medical care with support systems that address those other aspects of a person's being. (Cowie, 1993; OCRF, 1997; Cooper, et al., 2000; Strickland, et al., 1996);
- Culturally appropriate cancer care services require building an understanding of the importance of immediate, and sometimes extended family surrounding a patient (videos by AIAI, 1996; Jim Hyder Productions, for OBSP, undated; OCTRF, undated; Morning Dew Computer Productions, 1998; the *New Beginnings – Planning Cancer*

Care for Aboriginal Peoples, Cancer Care Ontario, 1997; Opie and Hackenberg, OBSP) undated; and Masi, et. al, 1993);

- Hospitals accommodating Aboriginal client's choices and wishes (Elliot, et al., 1999; Brant, et al., 1999);
- Impact of spiritual beliefs on cervical cancer prevention (Strickland, et al., 1996);
- Aboriginal community health representatives (CHR) were effective in communicating and encouraging and facilitating cancer prevention activities (Calam; Hodge, 1995; Thiemann, 1994; Lanier and Mostow in 1993);
- Lay health educators trained to promote screening (Brownstein, et al., 1992; Dignan, et al., 1995);
- Sensitizing medical personnel to work with Aboriginal clients (Elliot, et al., 1999);
- Training Aboriginal people to deliver services (Clarke, et al.; Masi, et al., 1993);
- Screening delivered locally, via mobile units or temporary clinics (OCTRF, 1996; Northwestern Ontario Breast Screening Program, 1992; Nutting, et al, 1994; Roubideaux, 1998).

8.5 Summary of Findings

There is agreement among community members that cancer services should be culturally sensitive. Just over one-third of participants (34%) felt that current cancer services were not culturally sensitive. They identified the fact that cancer services treat the disease rather than the whole person, a practice that runs counter to the holistic view of health held by many Aboriginal people. Service providers also identified a need to improve the cultural sensitivity of cancer service delivery.

At the same time, there is a strong sense that cancer services are or are becoming more culturally sensitive. 31% of respondents identified a positive trend in the cultural sensitivity of cancer services.

Culturally sensitive service delivery should include:

- Aboriginal staff on the care team, particularly in the role of a navigator/ cultural interpretor / liaison / care advocate; and translators available to assist Aboriginal cancer clients;
- Facilitation of access to and inclusion of traditional healers in the cancer service system; and
- The provision of information using Aboriginal examples in plain simple langugage, and in the relevant Aboriginal languages,
- Provision of information to service providers about Aboriginal cultural issues and the socio-economic situation of many Aboriginal clients

Accomodation for culturally specific needs, such as facilities for visits by extended family members, as well as opportunities for participation in Aboriginal spiritual and cultural practices are also identified.

Chapter Nine

Cancer Services and What is Needed

"Especially in the north there are no support services. Even in nearby urban centres, there are support groups but they are not geared to Aboriginal people and their culture."

9.0 CANCER SERVICES AND WHAT IS NEEDED

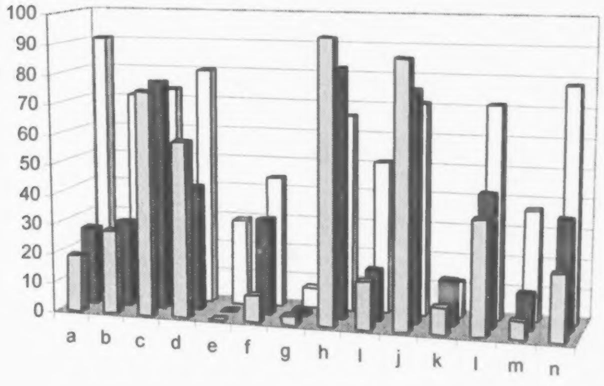
There is a widely held belief that Aboriginal people have not been adequately served by the existing cancer service system. This section of the report details what services are available to Aboriginal people, and what the service needs and priorities are.

9.1 Community Questionnaire

9.1.1 Availability of medical personnel

In the community survey, when asked what medical personnel are available to their community members, participants in each category responded as follows:

Figure 14: Percentage of Aboriginal Communities with Medical Personnel



	a	b	c	d	e	f	g	h	i	j	k	l	m	n
☐ Remote (32)	19	28	75	59	0	9	3	94	16	88	9	38	6	22
■ Rural (84)	26	29	77	42	0	32	2	83	17	77	15	44	12	37
☐ Urban Aboriginal Communities (41)	90	71	73	80	29	44	7	66	51	71	12	71	37	78

NOTE: percentage is the sum of total number of medical personnel (i.e. doctor) divided by the total number of participant communities by category (i.e. Remote)

Legend

a. Doctor (General Practitioner)
b. Nurse Practitioner
c. Community Health Nurse
d. Registered Nurse
e. Cancer Specialist
f. Traditional Healer
g. Traditional Healer in Cancer
h. Community Health Representative
i. Nursing Assistant
j. Personal Support Worker
k. Family Support Worker
l. Homecare Coordinator
m. Discharge Planner
n. Dietician/Nutritionist

The following table indicates the numbers and percentages of medical personnel in each category.

Table 1: Numbers and Percentages of Medical Personnel Available by Community Type

Medical Personnel	Remote (32)	Rural (84)	Urban Aboriginal Communities (41)
Doctor (general practitioner)	6 (19%)	22 (26%)	37 (90%)
Nurse Practitioner	9 (28%)	24 (29%)	29 (71%)
Community Health Nurse	24 (75%)	65 (77%)	30 (73%)
Registered Nurse	19 (59%)	36 (42%)	33 (80%)
Cancer Specialist	0 (0%)	0 (0%)	12 (29%)
Traditional Healer	3 (9%)	27 (32%)	18 (44%)
Traditional Healer in cancer	1 (3%)	2 (2%)	3 (7%)
Community Health Rep	30 (94%)	70 (83%)	27 (66%)
Nursing Assistant	5 (16%)	14 (17%)	21 (51%)
Personal Support Worker	28 (88%)	65 (77%)	29 (71%)
Family Support Worker	3 (9%)	13 (15%)	5 (12%)
Homecare Coordinator	12 (38%)	37 (44%)	29 (71%)
Discharge Planner	2 (6%)	10 (12%)	15 (37%)
Dietician/Nutritionist	7 (22%)	31 (37%)	32 (78%)

Not all the medical personnel identified are full-time positions. Some communities have doctors and nurse practitioners visiting their communities periodically, and some communities share doctors and nurse practitioners with other communities.

Overall, medical personnel are most readily available to the urban Aboriginal communities. Rural communities have a limited number of personnel available, while remote communities have the least availability of medical personnel.

The following sections describe the current availability of various types of medical personnel situated at or very near Aboriginal communities:

Medical doctors: Most urban Aboriginal communities have doctors, while less than 20% of remote communities have doctors. The figure above clearly illustrates the shortage of doctors in remote and rural communities.

Nurse practitioners: About one-third of remote and rural communities have nurse practitioners. Nurse practitioners are available to a majority of urban Aboriginal communities.

Community health nurses: Most communities, in every category, have community health nurses.

Registered nurses: A large number of remote, rural, and urban Aboriginal communities report having the services of registered nurses. Note that there may be duplication in reporting as some communities may have identified a single nurse as both a community health nurse and registered nurse.

Cancer specialists: No remote or rural communities have cancer specialists, either on site or nearby, while some urban Aboriginal communities have access to these specialists in nearby cities.

Traditional healers: Traditional healers are not widely available in Aboriginal communities. Less than 10% of the remote communities have traditional Aboriginal healers. Approximately one-third of other communities have a traditional healer. Availability of traditional healers specializing in cancer is very low in all Aboriginal communities.

Community health representatives: Most Aboriginal communities have community health representatives. It should be noted that CHRs are not doctors and only a few are trained nursing professionals.

Nursing assistants: Few communities, in any category, have the services of nursing assistants.

Personal support workers: Most communities have personal support workers.

Family support workers: Few communities have access to family support workers.

Homecare coordinators: Less than one-half of remote and rural communities have the services of homecare coordinators, while a majority of urban communities have these services.

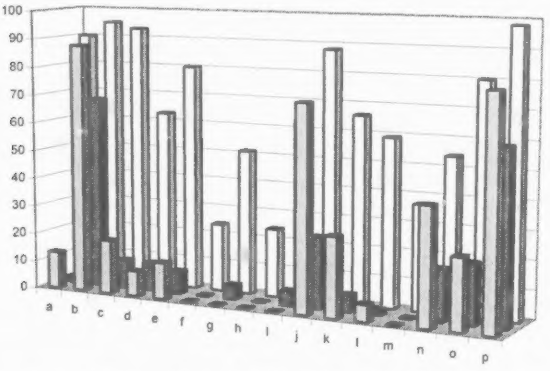
Discharge planners: Access to discharge planners is low in all Aboriginal communities.

Dieticians: Less than one-half of the remote and rural sites have dieticians, while majority of urban communities do.

9.1.2 Availability of Medical Services

In the community survey, when asked about what type of medical services are available to their community members, participants responded as follows:

Figure 15: Percentage of Communities with Medical Services



	a	b	c	d	e	f	g	h	i	j	k	l	m	n	o	p
☐ Remote (32)	13	88	19	9	13	0	0	0	0	72	28	6	0	41	25	79
■ Rural (84)	2	68	10	10	8	0	5	0	5	25	6	2	0	18	21	60
☐ Urban Aboriginal Communities	90	95	93	63	80	24	51	24	63	88	66	59	37	54	80	98

Legend

a. Hospital
b. Health Clinic
c. Public Health Unit
d. Sexual Health Clinic
e. Laboratory Testing
f. Regional Cancer Centre
g. Aboriginal Health Access Centre
h. Radiation

i. Breast Screening
j. Pap Testing
k. Prostate Screening
l. Colorectal Screening
m. Chemotherapy
n. Tele-Health
o. Palliative Care
p. Supportive Care

The following table indicates the number of medical services available in each category:

Table 2: Numbers and Percentages of Medical Services Available by Community Type

Services	Remote (32)	Rural (84)	Urban Aboriginal Communities (41)
Hospital	4 (13%)	2 (2%)	37 (90%)
Health Clinic	28 (88%)	57 (68%)	39 (95%)
Public Health Unit	6 (19%)	8 (10%)	38 (93%)
Sexual Health Clinic	3 (9%)	8 (10%)	26 (63%)
Laboratory Testing	4 (13%)	7 (8%)	33 (80%)
Regional Cancer Centre	0 (0%)	0 (0%)	10 (24%)
Aboriginal Health Access Centre	0 (0%)	4 (5%)	21 (51%)
Radiation	0 (0%)	0 (0%)	10 (24%)

Breast Screening	0 (0%)	4 (5%)	26 (63%)
Pap Testing	23 (72%)	21 (25%)	36 (88%)
Prostate Screening	9 (28%)	5 (6%)	27 (66%)
Colorectal Screening	2 (6%)	2 (2%)	24 (59%)
Chemotherapy	0 (0%)	0 (0%)	15 (37%)
Tele-Health	13 (41%)	15 (18%)	22 (54%)
Palliative Care	8 (25%)	18 (21%)	33 (80%)
Supportive Care	23 (79%)	50 (60%)	40 (98%)

Overall, as with medical personnel, medical services are more available to urban Aboriginal communities. Remote communities appear to have some medical services on-site, although in many cases the services may be situated outside their communities. There is limited availability of medical services in rural communities.

The following points describe the current availability of medical services in Aboriginal communities:

- Hospitals are available to a high percentage of urban communities. Rural sites have very low rates of hospital availability. A small number of remote communities report that they have hospitals, which include small clinic-type hospitals.
- Most Aboriginal communities have health clinics. However, not all of the clinics are staffed, and many have only part-time staff.
- Most urban Aboriginal communities have access to public health units. The availability of public health units is very low for remote and rural communities.
- Over one-half of the urban Aboriginal communities report that they have access to sexual health clinics, while other sites have very low availability rates.
- Laboratory testing is not commonly available in remote and rural communities. Urban Aboriginal communities have a high access rate to testing facilities.
- No remote or rural Aboriginal communities reported access to a Cancer Care Ontario Regional Centre, while about one forth of urban Aboriginal communities reported access to a centre.
- About one-half of urban Aboriginal communities have Aboriginal Health Access Centres. Only a very small number of remote and rural communities have these centres.
- Radiation treatment is not available on any remote or rural communities, while about one forth of urban sites report that they have access to radiation treatment.
- Breast screening services are available to a majority of urban Aboriginal communities. Remote communities report that they have no breast screening. Breast screening is available to a very small number of rural communities.
- Pap testing is available to larger numbers of communities. Most urban Aboriginal communities have access to pap testing. A majority of remote communities report that cervical screening is available to them, while only about one-quarter of rural communities have such screening.

- There is limited availability of prostrate screening[1] among First Nations communities. Almost one-third of remote communities report that prostate screening is available to them, while a very small number of rural communities have such services. About two-thirds of urban Aboriginal communities report that they have access to prostate screening.
- There is very limited availability of colorectal screening among remote and rural communities. However, over one-half of the urban Aboriginal communities report that they have access to colorectal screening.
- Chemotherapy is not available in remote or rural communities. Over one-third of urban Aboriginal communities have access to chemotherapy in nearby cities.
- Over one-half of urban Aboriginal communities report that they have access to tele-health services. Less than one-half of the remote communities have tele-health services, and only a small percentage of rural communities have access to such services.
- Palliative care is available to the majority of urban Aboriginal communities. One-quarter of remote communities have palliative care services, and a smaller percentage of rural communities report that they have such services.
- A majority of urban Aboriginal communities have supportive care services. A high number of remote communities report that they have supportive care, and over one-half of rural First Nations communities have supportive care services.

9.1.3 Links with Regional Cancer Centres (RCCs)

In the community survey, 43 out of the 157 communities (27%) reported that they had been in contact with a Regional Cancer Centre.

When asked what type of information or service their communities received from Regional Cancer Centres, the participants replied:

- information on Regional Cancer Centres(27);
- information on cancer and its impacts (20);
- workshops on cancer (13);
- Regional Cancer Centre staff visited the community (9).

Some communities reported that contact with Regional Cancer Centres also have included doctor-client consultation and visits from the Aboriginal Cancer Care Unit regional coordinators.

9.1.4 Links with other cancer services

In the community survey, participating communities were asked what links they have with cancer service agencies other than Regional Cancer Centres.

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[1] There are currently no formally structured prostrate screening programs being offered by Cancer Care Ontario. Prostrate screening is usually obtained through the family physician.

The most common links were with:

- Ontario Breast Screening Program, 105 of 157 communities (66%);
- Canadian Cancer Society, 83 of 157 communities (53%).

Other less common linkages (less than 20%) were also identified:

- Ontario Tobacco Strategy (23/157);
- Ontario Cervical Screening Program (21/157);
- Cancer Care Ontario Regional Council (19/157);
- Regional Networks for Cancer Prevention (14/157).

Other links with cancer services include health units, health centres and Internet information sites.

9.1.5 Supplementary financial support

In the community survey, 135 out of 157 Aboriginal communities (86%) reported that some **transportation costs for medical purposes** are covered for their community members by Health Canada, First Nations, or the Inuit Health Branch. Only 58 out of the 135 communities (43%) report that existing transportation services are adequate. Inadequacies were primarily related to lack of funding. Other transportation issues were identified:

- only one escort is allowed to accompany the patient even if the patient is very ill;
- travel from very isolated communities is difficult and expensive where cancer patients have to travel over frozen lakes or by helicopter.

It was reported that 96 out of 157 communities (61) have some **medical care costs** covered for their community members, through sources other than OHIP. 61 communities (39%) reported that no additional medical care expenses are covered.

Areas in which coverage is inadequate include:

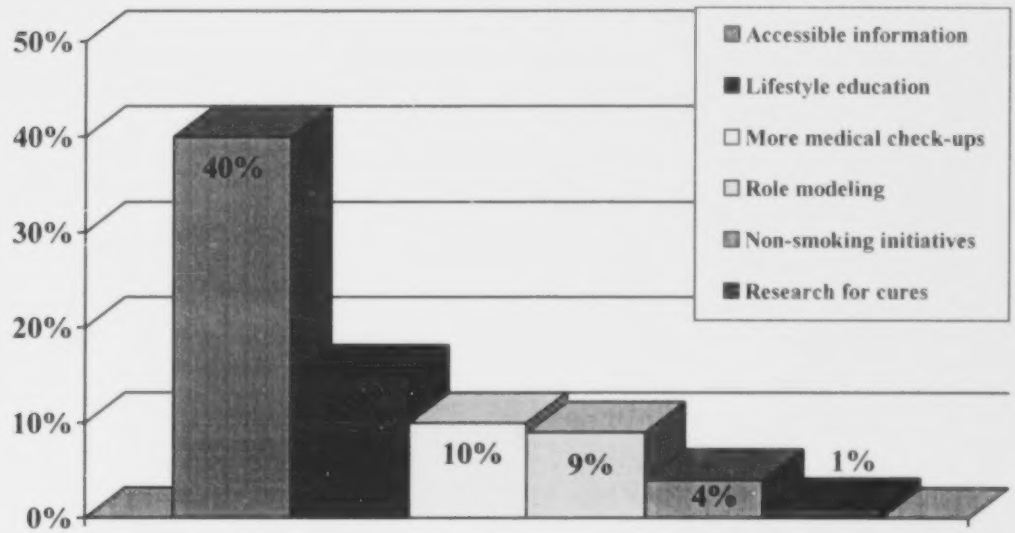
- accessing prescribed drugs that are not covered by health benefits;
- wigs and prosthesis;
- hospital beds for cancer patients living at home; and
- services of a traditional healer for those patients who chose traditional healing.

9.2 Community Interviews

9.2.1 Prevention services required

Study participants were asked what cancer prevention services were needed in terms of programs, policies, services, and community action.

Figure 16: Prevention Services Required



Note: Percentages may not sum 100 due to multiple responses and non-response. Base = 229 N = 181

40% (**91** respondents) wanted more **accessible information on cancer.** Respondents commented that many Aboriginal people are not knowledgeable about cancer. There is a need for community members to become familiar with the warning signs of cancer and preventative measures. There was an emphasis on developing a community awareness program to include breast self-examination, awareness on cervical cancer (Pap testing) and the different types of cancer. Programs that are developed should include the whole family and the broader Aboriginal community. Strategies discussed included the use of visual aids, and emphasis on the value on women's wellness groups to promote awareness.

15% (**34** respondents) advocated **lifestyle education** (from early childhood through adulthood), focusing on how to reduce the risks of each type of cancer through lifestyle choices.

A number of participants called for workshops promoting cancer awareness with a focus on prevention. Respondents recommended that health workers be provided with recent research on various types of cancer, their incidence, and ways in which risks can be reduced. It was also stressed that workshops be directed towards preventing cancers that are prevalent in specific geographic areas. Such workshops must recognize and follow a traditional, holistic approach.

10% (**23** respondents) said the best way to deal with cancer is through more regular **medical checkups.** A significant number of people were aware of cases where, by the time that cancer was diagnosed, it was too late.

Respondents identified a number of obstacles to early detection of cancer. First, many Aboriginal people have to travel distances to access screening. In most cases medical check-ups do not include pap testing and mammograms.

Some noted that the symptoms of cancer often do not present until the cancer is in its late stages. Others said that many people put off going for check-ups, even when they know something is wrong. Several health workers believed that better guidelines are needed to tell people when they should be checked or screened for different types of cancers, as well as when the annual follow up should be done.

9% (**21** respondents) emphasized the importance of **role modeling** by parents, teachers and elders. Adults, particularly those in positions of authority, must lead by example in the area of prevention practices.

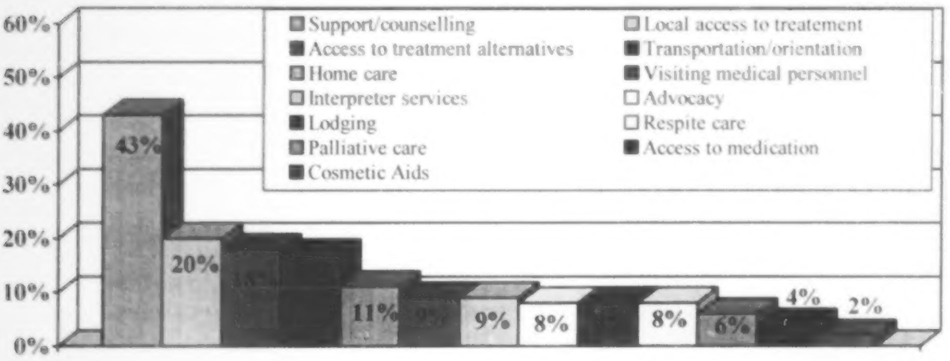
4% (**10** respondents) said **non-smoking initiatives** were a key component in preventative programming. Details of the recommendations are discussed in Chapter 7 of this report, entitled 'Use of Tobacco'.

1% (**2** respondents) said that directing more effort into **research for cures** is the most important action that can be undertaken to prevent cancer.

9.2.2 Services required for cancer clients

Community interviewees were asked what services are needed for cancer clients.

Figure 17: Services Required for Aboriginal Cancer Patients



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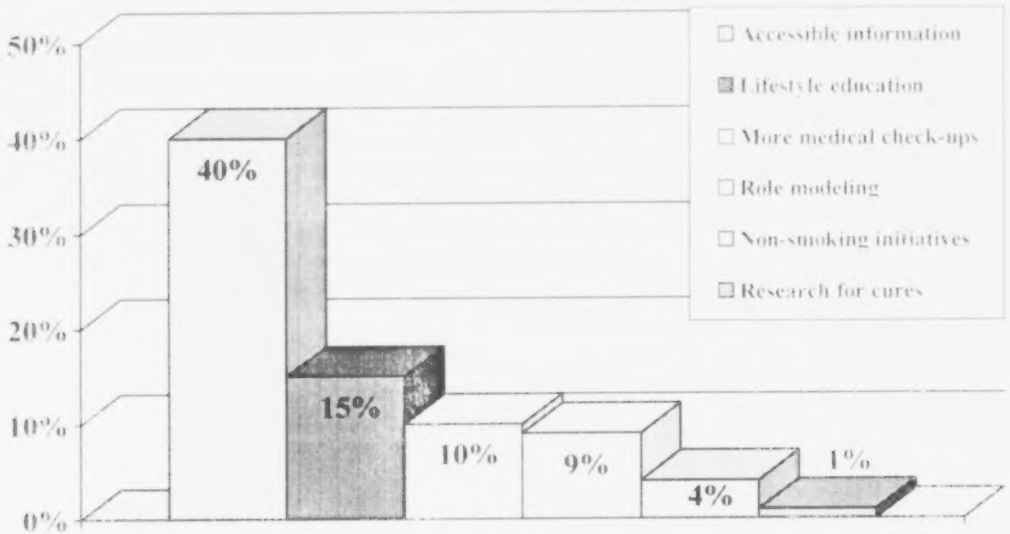

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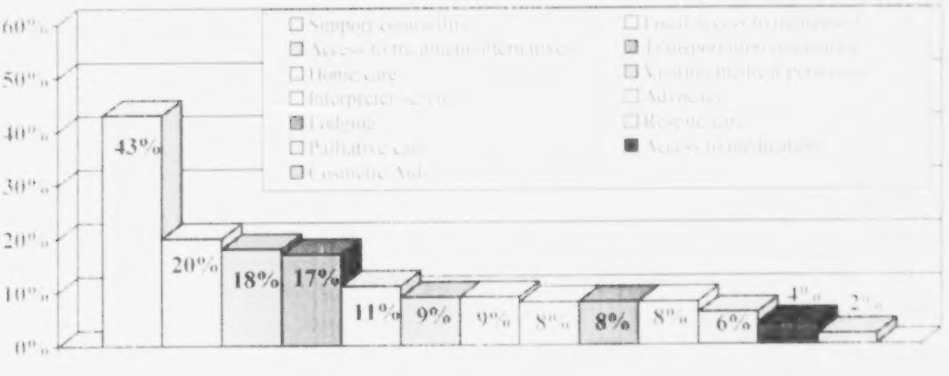

43% (**99** respondents) said the number one priority in terms of services is **support or counselling**. They described the need for a support system for cancer patients and their families that would enable them to access counselling and personal support for coping with the trauma of cancer. Cancer clients mostly need people that they can trust to reach out to them while they are in pain, or to listen when they are ready to talk.

A number of people remarked on how difficult it is for cancer clients to open up and talk about their feelings. Several others spoke of the need for more practical supports, such as child care services for parents undergoing treatment.

The majority of respondents who identified the need for support services spoke about the particular types of pain and confusion suffered by the families of cancer patients, and their need for support. The key message is that information be immediately available for those affected by cancer.

Many family members spoke about the creation of support groups. Several specified that support groups should be Aboriginal and conducted in a culturally appropriate manner. They also identified a specific need for support groups that deals with grief to help families cope in time of crisis and loss of family members

20% (**46** respondents) emphasized the need for **local access to diagnosis and treatment**, including **mobile screening services.** A number of respondents said they would like to see more treatment centres established in the north that would offer both diagnosis and treatment. Others recommended mobile clinics which would provide remote communities access to trained cancer technicians on a regular basis.

18% (**41** respondents) called for more abundant **information about and access to treatment alternatives.** Cancer clients and their families would like to know more about what treatment options are available. This information should also include traditional healing and other alternatives such as acupuncture, meditation, and relaxation. One health worker summed it up by saying, "*Choice is wonderful. It's so empowering to have the freedom to be able to choose something ...It would be nice if one day that the Aboriginal healing is recognized as one of the alternatives along with acupuncture, meditation, relaxation, chemotherapy...*"

17% (**40** respondents) saw **transportation** as a need. A significant number of people identified transportation as one of the major issues with regard to cancer services. There are many difficulties associated with transportation, particularly for cancer patients who live in remote areas.

Some health workers commented that their health centres provide transportation and some cancer patients reported that they had received assistance with transportation costs. However, there is inconsistency in the accessibility of transportation services, and a lack of understanding about which transportation services are funded. There is confusion on how to obtain assistance. Several cancer patients reported having driven themselves, or arranged their own transportation to treatment and did not get reimbursed because they were not aware that coverage might be available.

At the same time the respondents spoke about transportation, they also spoke about the need to have an escort accompany the patients. The escort would be able to communicate between the health care professionals and the patients, translating between English and the Aboriginal language.

11% (**25** respondents) stressed the importance and benefits of **home care** for cancer patients. Most respondents agreed that the best place for them is at home, provided they can be properly cared for. Cancer patients themselves strongly prefer to be at home. Many felt that care services can be delivered more cost effectively within the community.

However, the interviews revealed deficiencies in the current availability and quality of home care services for Aboriginal cancer patients. Health workers told how recent provincial cutbacks to Community Care Access Centres have worsened the problem. Family members complained of being inadequately equipped to manage a cancer patient at home. In this respect, their comments were particularly moving because they spoke of the hardship, lack of resources and lack of support from the medical community when they were faced with caring for a weak and suffering loved one. There were examples given about this situation: *"When you're bringing a patient home from the hospital ... We have absolutely nothing. I tried to care for this man that couldn't stand. Nobody here wanted to be bothered with us - nobody. And I thought, 'I got him on the couch, how am I going to get him out of there?"*

While some organizations were identified as providing home care, it appears that services are difficult to access for families who live on reserves, due to jurisdictional boundaries.

9% (**21** respondents) requested **more visiting medical personnel.** Respondents reported shortages of medical professionals, particularly physicians. Ideally, there should be enough medical staff to provide home visits.

9% (**20** respondents) identified the need for **Aboriginal interpreters/translators** to be part of the hospital staff. Those respondents often added that the role of the translators needs to be broadened to provide more practical assistance to patients who are left in the urban centres for treatment for long periods of time.

8% (**19** respondents) identified the need for **advocacy**. A common theme in this area was that Aboriginal people often feel confused and disoriented during cancer treatment, particularly in large urban settings far from their communities. They do not question authority or ask for further information or clarification. Some do not speak up for their rights, particularly when they are sick and weak.

8% (**18** respondents) identified the need for **lodging**, especially for the family members of cancer patients who need to be nearby during treatment. While there appears to be adequate lodging for cancer clients, accommodations for families are hard to find. Some commented that they found the hotels in cities where they travelled for services expensive and less than adequate. Respondents called for funding to put the families up in a hotel for however long the patient is in the hospital, so they can be there at all times.

8% (**18** respondents) described a need for **respite care/caregiver support.** Family members in this group described practical difficulties, stress and exhaustion that they faced in trying to care for a family member with cancer. Family members and health workers alike called for in-home respite care to support families caring for cancer patients at home.

6% (**14** respondents) identified a need for improved access to **palliative care**. They described a situation where many cancer patients want to die at home, but the support is not there to make it possible. Health workers agreed that, by and large, the service systems are not set up to accommodate patients who want to die at home. Some complained about the excessive amount of paper work that has to be completed to enable someone to die at home. Respondents made a number of recommendations with regard to palliative care including:

- training in palliative care for health workers and family member;
- involvement of traditional healers to help dying cancer patients accept their journey; and
- a special palliative care facility for Aboriginal patients

4% (**9** respondents) identified issues related to **access to medication**. For the most part, this was not a concern. Some mentioned that programs such as the First Nation and Inuit Health initiative covered the cost of their drugs, for which they are grateful. However, access to medication sometimes becomes an issue for people in rural and remote areas where there is no pharmacy.

2% (**4** respondents) identified the need for **help with cosmetics** for cancer clients. Specifically mentioned was help to find suitable wigs and breast prosthetics.

9.3 Service Providers' Questionnaire

9.3.1 Services provided

Service providers were asked about what services were provided by their institutions in prevention, treatment and aftercare.

Prevention: Fifty service providers reported providing the following prevention services:

- breast screening, (27/50);
- cervical screening, (19/50);
- smoking cessation programs, (18/50);
- other programs such as colorectal scopes, and testing to detect prostate and ovarian cancers, (12/50); and
- preventative education on breast, cervical or other cancers, (2/50).

Other programs offered by single agencies include health promotion, group sessions for sexual assault, education on cancer risk factors, promotion of early detection, referrals to smoking cessation programs, nutritional counselling, prevention in physical activity, and sun safety issues.

Treatment: 20 out of 50 have the facilities and staff that offer chemotherapy. 16 of the 50 have surgery performed on site. 14 offer clinical trials, and eight are able to offer radiation treatment.

Aftercare: Almost one-half (23 out of 50) of the service providers have programs that provide palliative care. 20 facilities deal with pain and symptom management for their clients, and the same number offer supportive care and counselling. 17 provide follow-up assessments.

Services specifically developed for Aboriginal cancer patients: Less than one-half (22 out of 50) are involved in networking or make referrals to Aboriginal health workers. Only four of the agencies have specific prevention programs geared to accommodate First Nations people. Other programs designed specifically for Aboriginal clients include:

- resources to offer translation services when required, (15/50);
- accommodation for Aboriginal ceremonial practices, (12/50);
- referrals to Aboriginal healers, (9/50);
- traditional foods, (6/50);
- staffed with Aboriginal personnel, (6/50)
- signs or notices in Aboriginal languages and/or syllabics, (4/50);
- lodging or hostels specifically for Aboriginal people, (4/50);
- orientation to the institute or the city, (4/50);
- screening awareness, (2/50);
- education on breast and cervical cancer prevention, (1/50); and
- links with Aboriginal organizations, (1/50).

One agency pointed out that access to traditional foods was limited due to restrictions outlined in the health regulations. One agency responded that they have no services specific to Aboriginal clientele.

Organizations described how they ensure that Aboriginal people have access to cancer services by:

- creating awareness of services through community health workers, (25/50);
- having a referral system in place, which links the community to outside services, (16/50);
- media publicity and advertising (radio, newspapers, and television), (13/50);
- offering translation services, (11/50);
- hiring Aboriginal staff members, (11/50);
- offering transportation services, (9/50);and
- providing tele-links, (3/50).

Other methods included prevention and promotion programs (2 mentions) and the hosting of a cancer awareness week. One respondent reported that they provide the same services as they do for the general public.

9.3.2 Linkages and networking

Service providers described **other organizations** in their areas **that provide cancer services for Aboriginal people**. Forty percent (20 out of 50) indicated awareness of other services in their areas. The services identified include:

- First Nations health services (11/50);
- hospitals (6/50);
- Cancer Care Ontario Regional Cancer Centres (4/50);
- Canadian Cancer Society (4/50);
- urban health centres (4/50);
- Native Friendship Centres (4/50); and
- Aboriginal organizations (3/50).

13 of the 50 responding agencies stated that there are no other local organizations providing cancer services for Aboriginal people in their areas.

Service agencies described the networking **links** they have, and the **ways in which they reach out to Aboriginal people:**

- distribute brochures to First Nation communities, (18/50);
- make community presentations, (18/50);
- have developed educational materials specifically for Aboriginal people, (16/50);
- include direct involvement of Aboriginal people in their planning, (14/50);
- Aboriginal advisors participating in committees, (12/50);
- outreach clinics for Aboriginal clients, (8/50); and
- outreach workers who create awareness among Aboriginal people, (4/50).

Other programs described by single agencies include contact with community workers, initiatives to translate cancer information into Aboriginal languages, and health fairs and displays.

The following gaps in cancer services for Aboriginal people were identified by the fifty participating cancer agencies:

- programs and services sensitive to Aboriginal people, (6/50);
- culturally appropriate promotional materials, (4/50);
- staff training to facilitate a better understanding of Aboriginal people, (4/50);
- shortage of medical personnel near Aboriginal communities, especially in the north, (4/50);
- support services with social workers and health workers, (2/50);
- cross cultural awareness – "knowing the differences", (2/50);
- translated materials, (2/50);
- specific prevention services, (2/50);
- awareness of risk factors, (2/50);
- development of educational material for schools, (2/50);
- transportation assistance to get to cancer services, (1/50);

- referrals for further tests outside of the local communities, (1/50);
- ability to offer care for Aboriginal clients closer to their home, (1/50);
- lack of meeting basic health needs, (1/50); and
- the need for access to detection, treatment and palliative care services, (1/50).

9.4 Service Providers' Interviews

Service provider discussion groups had wide-ranging discussions on the gaps, needs and priorities in cancer services for Aboriginal people. In many cases, participants identified late stage diagnosis as the most critical result of service gaps. Aboriginal people have low participation in screening programs. Larger urban centres' screening relies on self-referral. There is a lack of information about cancer prevention reaching the Aboriginal people. Timing in early diagnosis is a huge factor in cancer care.

In discussing **culturally specific needs,** agencies identified changes they would like to see in their own organizations and in the cancer service system generally. These changes include:

- more research specific to Aboriginal people;
- plans and mechanisms to gain credibility and trust in the Aboriginal community;
- access to translation services for Aboriginal languages;
- access to traditional Aboriginal healers;
- a special room or facility for traditional practices and ceremonies within their agency;
- more links with Aboriginal agencies;
- more Aboriginal medical professionals.

The following sections discuss the various issues and gaps in providing cancer services to Aboriginal people in more detail.

9.4.1 Shortage of doctors and other medical personnel

Discussion group members raised concerns about the **lack of physicians** in Aboriginal communities. The Regional Cancer Centres see many patients who do not have family doctors. Participants pointed out that in many communities a doctor only comes to the community every month or two. Many people in the north have no family doctor, and there is a high turnover rate of doctors who practice in the north. They noted that the lack of doctors in these communities can lead to late referral for diagnosis and treatment. The shortage of doctors may account for gaps including a shortage of information about cancer, lack of early detection, low participation in screening, and the difficulty many Aboriginal people have in developing trust in the health care system.

The **lack of cancer experts** is leading to significant time management issues for medical staff who organize screening, testing, and other aspects of cancer care. Doctors and oncologists have too much to cover in a single trip to a northern community. Consequences include misdiagnosis, late diagnosis or late intervention. In addition, one participant felt that the outdated radiology equipment is 'appalling,' and more attention to quality assurance of services is in order.

9.4.2 Access to cancer services

Participants pointed out the need for strategies to **get diagnosis and care service "out to the people"** as opposed to having people travel to obtain services. The difficulty in accessing screening and other prevention services may account for the fact that many Aboriginal patients are not seeking diagnosis and treatment early enough.

Concerns about **breast screening** were highlighted as a separate gap. The lack of access to screening and treatment are apparent, and awareness about breast cancer prevention needs to become more open in the communities. It was stated that *"There should be a real push for mammograms and pap smear testing in Aboriginal communities".* Agencies and physicians are fully aware that access to breast screening is difficult for Aboriginal women, and they acknowledge special challenges for women in the north who need to travel by air for screening.

Service providers believe that people in the south have more regional access to services. They feel that treatment and care should be closer to the patients' homes. Attempts made to ameliorate the difficulties of having to travel for services are not always successful. In cases where lodging is offered, one participant stated "*Every single person refuses to stay at the Lodge*". The participant felt that their reasons stem from the fact that the client's family can not stay with them.

The issues of **after care and follow-up** were also raised as a concern among the service provider discussion groups. Improvement in follow-up care is thought to be overdue. Agencies listed follow-up care for children in the north, after-care accessibility, and complications due to missed appointments contributing to problems in cancer care. Once diagnosis has taken place, issues of access to psychological services, home care education and support groups are not being adequately addressed in the communities.

Many participants identified the need for improvements in both **supportive and palliative care** for Aboriginal patients. They pointed out that both clients *and* family members need help. The need for counselling and support groups was identified in the interviews throughout the province.

One participant identified issues surrounding the availability of narcotics for palliative care on reserve communities, and complications of administration and monitoring the medication in remote locations. They felt that caregivers need specialized training that is client-centred or patient-focused.

9.4.3 Transportation

Those working in cancer care agencies have a unique perspective on how various issues of transportation can affect people's behaviours. They find that reserve residents often encounter difficulties getting to the health care facilities which results in missed appointments. Particularly in the north, the question of making arrangements for prevention work poses difficulties. For example, a person would have to convince the health service that it was necessary to fly out for a mammogram when there were no indications of ill health. In considering solutions, they talked about the possibility of mobile screening and also of its high costs.

One group felt that Northern Travel grant funds are insufficient. Another added that there is a lack of Aboriginal funds to transport escorts with the cancer clients. One service agency pointed out that only Aboriginal people in the city have access to public transit to get to screening, and that all other Aboriginal clients face higher costs of traveling to screening clinics. Jurisdictional issues complicate the issue of coverage.

9.4.4 Financial support and medical coverage

Several participants raised concerns about access to Health Canada's non-insured health benefits and First Nations assistance when confidential information must be given to clerks in small communities in order to get coverage or reimbursements. Another issue raised is the inequities and favouritism that can occur when approval or submission of claims depends on local clerks in small communities. In another area of the province, service providers observe that clients are unaware of which health care services are covered. They feel that people need to be informed about what coverage they have access to. They see people struggling financially, and struggling to balance financial issues against health care.

In the issue of travel, concerns over jurisdictional issues arose. There is confusion between provincial and federal jurisdiction on the question of medical coverage: "*Who will pay for what?*". One of the cancer centre discussion groups talked about the confusion and disagreement about which level of government has the responsibility to provide health care services to First Nation populations and under what circumstances. This has an effect on people's comfort level and impacts on their willingness to undertake medical care. Complexity and expense may cause delays in people investigating symptoms and seeking testing and treatment.

9.4.5 Culturally appropriate services

Many service providing participants identified a need to provide services in a culturally appropriate manner, and to make the effort to accommodate Aboriginal cultural practices where possible. They also identified a need to provide some support to help Aboriginal people to bridge the cultural gap between their home communities and the communities in which cancer services are provided. Several participants felt that the cultural issues affected the ability of Aboriginal patients to develop trust in the cancer care team, and this affects the outcome of their treatment.

They identified several major areas of concern:

- staff need training on cultural awareness;
- accommodation for traditional practices and extended families;
- culturally appropriate communication to Aboriginal people and communities;
- language issues; and
- need for an Aboriginal patient liaison /advocate.

Staff Need For Cultural Awareness: They identified a key issue as the lack of understanding between the service provider, the patient and the family.

Four discussion groups identified the need for continuous cultural awareness training for medical workers. They feel that staff orientation is required to facilitate an understanding of and sensitivity to Aboriginal culture. They point out the differences between various parts of the province, between Aboriginal community affiliations and the diversity of their languages and dialects. Caregivers need to understand where different culture groups are coming from, what is available to Aboriginal people, what they believe in and what can help them better cope in the medical system.

One group identified the need to sensitize health care facilities on the value that Aboriginal people place on family and extended family, as many health care providers witness large numbers of family members present on oncology floors.

Accommodation for Traditional Practices and Extended Family: Three of the groups talked about cultural differences in terms of respect for traditional medicines. They feel that spirituality greatly impacts Aboriginal clients but also note the difficulty to accommodate opportunities within the system for spiritual practices like smudging, which require sprinkler systems to be shut off. In another case the physician would not allow flowers or an eagle feather in the patient's room. The service providers expressed the need to build an understanding between Aboriginal and medical staff about respecting one another's values.

Acknowledgement of Aboriginal methods for treating disease is also identified as a need. The service agencies note that cancer treatment in the current facilities seems intimidating, invasive, and very impersonal to Aboriginal clients due to the lack of cultural sensitivity. Three pointed out the need for a spiritual component in the treatment, as well as access to traditional treatment.

Culturally Appropriate Communication to Aboriginal People and Communities: Participants made suggestions about culturally relevant materials and programs. One participant suggested an Aboriginal Health Access Centre, offering interpreters and cultural interpretation and teachings. One group hoped to link this Centre with the Regional Cancer Centres, and added that the Aboriginal Advocacy Committee produces video and a resource manual on Aboriginal people and cultural sensitivity, which positively bridges the cultural gap.

Service providers identified the need to incorporate Aboriginal material into palliative care. They feel that communities have resources that cancer patients can draw on to make palliative care a reality.

As well, service providers would like more education on Aboriginal terminology, values and beliefs. The Regional Cancer Centres need to become aware of the issues and needs of Aboriginal people to better establish knowledge and education, and to develop communication initiatives.

Service providers talked about ways to promote or enhance cross-cultural awareness. They suggested the hosting of public forums to explain cancer. One group would like to see efforts placed on the understanding of how and why Aboriginal people have certain beliefs about cancer.

Language Issues: One discussion group brought up the importance of language and pointed out the need to present materials in the appropriate languages. A physician added that cultural sensitivity creates a big gap in communication with Aboriginal people.

Many Aboriginal patients, especially older ones, are too proud to admit that they do not understand what the doctor is telling them. This is a particular problem with the terminology used in cancer services.

Aboriginal Patient Liaison/Advocate: In five of the discussion groups, service providers talked about the need for a counsellor-type liaison between Aboriginal cancer clients and service providing facilities. They observe that clients have difficulties in dealing with the disease, and the frequency of instances where issues of poverty and abuse are complicating factors. Service providers noted a mistrust of conventional medicine among Aboriginal clients and they felt that an advocate who '*walks beside them*' would be helpful.

Service provides believe that advocates working to create awareness on traditional medicines and cultural knowledge would help. It was reiterated that Aboriginal service staff are needed to serve as liaisons and that learning is required from both the service providers and Aboriginal patients.

Communication and isolation issues were discussed. In the interest of their Aboriginal clients, one of the service providers expressed the need for more Aboriginal volunteers. Another talked about language barriers and the difficulty in communicating with patients. Concerns were also raised about isolation and its impact on the patient's emotional well-being.

9.4.6 Outreach and networking

Participants suggested building and strengthening networking support and referrals to help Aboriginal cancer clients. Another added that service agencies need to know what links to the Aboriginal community will work best, observing that most Aboriginal communities have a sophisticated network that could be used to improve the effectiveness of outreach efforts.

Better communication between Aboriginal communities and cancer agencies was also strongly recommended. Three agencies cited the importance of strengthening connections with the Aboriginal communities, and two phrased it as making links directly with community members. Two of the organizations suggested that working with community-based health workers may improve linkages. Other participants recommended working with the schools to get the message out to youth.

Service providers also suggested the following strategies:

- working with CCO on developing culture specific programming;
- collaboration with other programs (such as diabetes);
- advocacy work for Aboriginal patients;
- efforts to meet the linguistic needs of Aboriginal clients;
- offering of health services closer to home;

- involving Aboriginal communities in cancer service planning; and
- promotion of awareness about Aboriginal people.

When asked about gaps in cancer care, one traditional healer stated that the gap between Western and traditional beliefs is the biggest challenge. Acknowledgement of this gap is growing. From a physician's point of view, the need to work on building common ground is the apparent starting point.

9.4.7 Education and awareness

With the recent increase in cancer in Aboriginal communities, people are still unfamiliar with the disease and how to deal with it. More Aboriginal people need to know more about cancer, the treatments and the side effects. The message that cancer is not a death sentence is a priority.

Service providers feel that Aboriginal people require a better understanding of cancer treatment. They feel that people need to be informed about treatment options. Community members, care givers and patients need to understand that many cancers are treatable. Financial resources are needed to implement this education process.

The agencies believe that patients need to build a good understanding of their disease and the tools to cope with it. Aboriginal people need be taught about what cancer is, the different types, treatments, success stories, prevention and healthy lifestyles, with a special campaign about the negative affects of smoking tobacco. In addition, they would like to see a better understanding among Aboriginal people of what to expect once a diagnosis is made. They need to know when, where, and how to seek support through their family, community services, the Regional Cancer Centres, and other available resources. Their orientation, and perhaps healing, needs to come from their culture. A good example is through programs such as the programs that offer transportation of Aboriginal women for cervical screening. One of the physicians observed that a personal approach is needed to create better relationships with Aboriginal patients.

Health providers feel there is a general lack of education about cancer screening. Some feel that this is a major gap, because the Aboriginal population is so hard to reach. For example, it is difficult to teach healthy choices when rural or isolated Aboriginal communities face difficulties in obtaining fresh fruits and vegetables. Most of the remote communities also lack many of the basic services that exist outside the community. Service providers commented on the need for stronger leadership and connections with community health providers. One physician expressed the belief that education has to start in school and that prevention has to begin at the grassroots level. He felt that awareness materials should be culturally appropriate and geared toward the Aboriginal reader. He pointed out that not all Aboriginal people follow traditional ways and that education materials should be geared to address the needs of all Aboriginal people, whether they are traditional or non-traditional.

Service providers would like to see a heightened community consciousness about cancer. They recommend alerting leaders about the importance of educating the people to ensure that continuous cancer awareness is established in the community. More initiatives and approaches are required in all areas such as cervical screening, tobacco awareness, and political issues; they endorse the need to put financial and human resources into this effort. They feel that health care providers in Aboriginal communities require more training on the disease of cancer and all its impacts.

Service providers offered suggestions on how to approach the education process. A traditional healer suggested community workshops on cancer awareness. Other ideas generated from the service providers included job fairs, health fairs, pow-wows, and drama. Specific printed materials on cancer, such as pamphlets, posters, and handbooks and orientation videos on cancer were suggested. One physician hopes to see a clearinghouse or resource centre developed to enable easy access to these resources. As well, it was expressed that an ongoing needs assessment and evaluation of the approaches be conducted in the Aboriginal communities.

9.4.8 Research

The issue of identifying Aboriginal people within the cancer system has posed a challenge in conducting research in the Aboriginal population. The agencies would like **access to statistics** in order to observe cancer patterns within the Aboriginal population. Research may provide valuable information to develop approaches and strategies within the Aboriginal population.

9.5 Secondary Research

Harvald, (1990), provides an example of how the Danish Cancer Society has evolved to support Inuit patients and their relatives. Their programs address loneliness and language interpretation, and the research refers to provision of a Greenlandic nurse with oncological training to work with their patients. Isolation can be difficult for all those affected by cancer and location of the patient or services closer to the community may be impossible.

Aboriginal cancer support systems, survivor groups, services, and counselling have begun to form in various parts of the continent, and a national effort with information on-line now exists in the United States. Projects aimed at taking away the fear of cancer and dying are beginning to bring the importance of open discussion about cancer into the communities, using cultural sensitivity and traditional approaches to awareness, prevention and healing. Again, many of these projects require establishing collaboration between the medical professionals and people with experience in Aboriginal cultures. The National Native American Cancer Survivors' Support Network in the United States keeps an up-to-date list of their programs available (see their listing in Appendix D). A series of support booklets and videos was developed by Native American Cancer Initiatives in 1998 to support the newly diagnosed patient. They describe reactions, treatments, options and outlook. These materials can be used to supplement existing groups or to support the formation of a cancer support group.

In creating cancer awareness among Aboriginal people, community recruitment is seen as beneficial efforts to reach individuals. Elliot, et al., (1999) directly addresses this topic and other studies incorporate it into their prevention strategies. Hosting talking circles and having elders in to speak to community groups have proven to be an effective means of communication.

Concerning support for Aboriginal cancer clients, Dumond and Bates, (undated) described an Ontario First Nations community approach to helping cancer patients and their families, describing services, accessibility of services to them, and the formation of a support group. Information on community care and experiences with a cancer support group can be located through the Gane Yohs Community Health Centre on Six Nations (see Appendix D).

Developing programs and materials on cancer support are: Circle *of Hope – A Journey of Survival* – video (undated); *Inventory of Cancer Care Activities and Programs Targeted to Aboriginal People in Canada*, Medical Services Branch, Health Canada, (2000)*; Current Cancer Care Initiatives in the Aboriginal Community report*, Cancer Care Ontario, (1996); First Nations Breast Cancer Society video, (1996); Brownstein, et al., (1992); Strickland, et al., (1996); Brant, (undated); Burhansstipanov, (1998/2000); and Kottke and Trapp, (1998). Experiences with the Greenland Inuit are described in Harvald, (1990).

The cervical cytology screening project for urban Aboriginal women in British Columbia, Hislop, et al., 1996, and Clarke, et al., undated, approached awareness with careful consideration to the culture, addressing issues such as modesty and privacy. They also described sensitivity training among clinical personnel who serve Aboriginal women. Other projects concerned with cultural training for personnel include Brant, et al., (1999), on working with Plains Indian women in the United States, and Kottke and Trapp, (1998) in their training research at the Mayo Clinic in Rochester, Minnesota.

The *Walking the Journey of Womanhood* project developed for Yakama women in Washington, Strickland, et al., (1996), used their traditional worldview, isolating the stages of a woman's life and her role in the community to reinforce the value of women staying healthy. A pilot project implemented by the Center for American Indian Research and Education in California (Hodge, et al., 1998) included ideology about traditional and medical health care, bringing traditional healers and ceremonies into discussion groups, and with women's talking circles on cervical cancer and prevention. Their work included traditional storytelling, myths and legends to promote cancer awareness.

Resources geared to Aboriginal males are scarce. Favourable differences, and for many cancer sites, in fact, *lower* cancer incidence among Aboriginal people, have been shown in studies that compare their rates with other races. However it must be noted that comprehensive and longitudinal research is scarce in Canada. The major concern about Aboriginal people remains improving earlier stage diagnosis and increasing survival rates for cervical and breast cancer in Aboriginal women. These have prompted early detection efforts but in the context of Aboriginal healing, only one video specifically geared to Native American male cancer survivors was found (Morning Dew Computer Productions, 1998).

Efforts to increase palliative care were described by the OCTRF (Cancer Care Ontario), 1996; Cooper, et al. (1991) and the Northwestern Ontario Cancer Centre, (1997). A description of long-term home/community care can be found in the Gane Yohs Community Health Centre on Six Nations (2000) who also host an active cancer support group. These were examples where patients hoped to continue to either care for themselves, support one another, or stay in their community as long as possible.

Rehabilitation and palliation were included as part of the proposal for *A Comprehensive Cancer Control Program for the Sioux Lookout Zone and the Town of Sioux Lookout and Area* in Northwestern Ontario Cancer Centre, Community Cancer Care Program, (1997). It proposes collaborations among local agencies, and outlines plans to tackle the challenges faced when providing services in a unique geographic location.

9.6 Summary of Findings

The findings from the community members and from the service providers interviews and surveys were consistent. There are gaps in the cancer care services provided to Aboriginal people in Ontario.

There is a dramatic shortage of medical personnel and services available to Aboriginal communities, particularly in the rural and remote communities. There is a chronic shortage of doctors, and many Aboriginal people do not have a family doctor. Members of rural and remote communities currently have to travel significant distances to participate in screening programs, or to access diagnosis and treatment services. Service providers expressed concerns that these gaps were responsible for the low participation rate of Aboriginal people in screening programs, leading to the observed phenomenum of late-stage diagnosis. Both the community members and the service providers would like to see more cancer services delivered closer to the Aboriginal communities.

It is clear to both community members and service providers that many Aboriginal people want to know more about cancer. There was a universal call for information/education /awareness programs to ensure that people in Aboriginal communities know what cancer is, what the early warning signs are, what prevention activities are available and how they should be used, as well as what cancer treatement services are available. It is hoped that increased awareness will lead to greater participation in screening programs and earlier detection of cancers, which will ultimately reduce the burden of cancer.

Both community members and service providers identified a need for cancer services to be delivered in a more culturally appropriate manner. They recommended efforts to accommodate traditional practices, to train medical staff about the Aboriginal world view, to provide for language needs and to establish, more respectful links to traditional Aboriginal healers.

One of the key mechanisms identified to assist Aboriginal clients to bridge the cultural differences was a "navigator". Service agencies could provide an Aboriginal patient liaison staff member to help patients to navigate the medical system so that patients and family members can understand and make choices in that system, and a navigator would also help service providers to understand and respect Aboriginal patient needs and wishes.

Other critical needs identified include:

- supportive care and counselling;
- more access to treatement alternatives, including traditional Aboriginal treatement;
- more aftercare, including home care services and palliative care;
- funding support for transportation and uninsured medical expenses;
- clarification of jurisdiction between what is provided by the federal government and what is provided by the provincial government.